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**At a crossroads in care: the experience of individuals
with Down syndrome and dementia**

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ABSTRACT

The awareness that people with Down syndrome are at risk of dementia at a younger age, even in their forties or fifties, brings to the fore a group previously excluded from research. Literature documents the experiences of people with Down syndrome and, separately, that of people with dementia. This includes knowledge of individual experiences through self-advocacy, inclusion in service development, policy and research, and the drive for a more person-centred way of providing support. We do not have the same knowledge about the experience of individuals who have both Down syndrome and dementia.

Research literature suggests that people with Down syndrome are already marginalised before a diagnosis of dementia, due to society's interpretation of their intellectual disability. The first quantitative stage of this longitudinal, mixed method study demonstrates the awareness of carers and actions taken post-diagnosis, highlighting the social exclusion experienced by people with Down syndrome. The second more substantive, qualitative stage considers factors that impact on the experience of individuals with Down syndrome and dementia. My observation identifies factors that highlight the process of further social and cultural marginalisation after a diagnosis of dementia. Findings are initially based on a thematic analysis of my transcribed data to develop case studies, followed by cross case analysis. Emerging issues from both stages of the research suggest commonality of experience in relation to the lack of a shared diagnosis, lack of recognition of

sense of Self or identity, failure to recognise the importance of adapting communication to enable social interaction, a readiness to define a person by their situation rather than as an individual, and my observations of the impact of staff. I suggest that care and support for people with Down syndrome and dementia is at a crossroads, with an absence of shared learning between intellectual disability services and dementia services.

I demonstrate how far I have been able to synthesise my approach to methodology and methods of data collection to enable the inclusion of a group previously excluded from research, incorporating both verbal and non-verbal exchanges as dementia progressed. Despite individuals with Down syndrome and dementia not being visible in service development and policy, it has been evidenced that their participation in research is not only possible, it is essential, as this group continues to enjoy a longer life expectancy that brings with it an associated risk of dementia.

DECLARATION

I hereby declare that this thesis has been composed by me and that the research on which it reports is my own work. The content has not been submitted for any other degree or professional qualification.

Karen Watchman

2013

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CHAPTER ONE

INTRODUCTION

1.1 Introduction

There are a growing number of people with Down syndrome who are developing dementia at a considerably younger age than is observed in the general population. Whilst we are beginning to understand more about how some older people construct their experience of dementia, we do not have the same awareness and insight into the experiences of people with Down syndrome. This is due to the complexity of including people with Down syndrome and dementia as research participants and a subsequent lack of available literature. Typically, people with Down syndrome will experience stigma and marginalisation even before their diagnosis of dementia. This can be attributed to society's perception of their existing intellectual disability, combined with increased cognitive impairment associated with the progressive nature of dementia.

Drawing on a social constructionist approach, this thesis is an exploration of the experiences of people with Down syndrome and dementia. Based on my findings, I have been able to highlight the continued process of marginalisation of people with Down syndrome after a diagnosis of dementia, raising issues at both societal and cultural levels. This chapter gives brief background information about Down

syndrome and dementia, before considering my motivation for this topic. I explain how the research questions were developed in two stages to include firstly carers and then people with Down syndrome, followed by an explanation of the structure of the thesis.

1.2 Background

Down syndrome is a congenital condition identified at birth and present from the point of conception. It results in varying degrees of intellectual disability and is the most common congenital syndrome, as well as being the one most frequently recognised due to its resulting physical features. Historically, people with Down syndrome had a short life expectancy, the average age of death being nine in 1929, twelve in 1947 and eighteen in 1961 (Bittles and Glasson, 2004). As a result of an increase in medical interventions, with greater life and social opportunities, people are now living for longer. A life expectancy of over sixty years is expected for many people with Down syndrome (Holland, 2000). This longevity has led to the knowledge that there are a number of illnesses in mid and later life that people with Down syndrome are susceptible to, one of which is dementia. Adults with Down syndrome are at a significantly higher risk of getting dementia at an earlier age, with onset recorded by Tyrell et al. (2001) to be at an average of 54.7 years.

Dementia is an umbrella term for a number of different conditions affecting the brain, each of which is characterised by progressive impairment, something that affects the functioning of the mind or body of an individual. The most common

forms of dementia are Alzheimer's disease; vascular dementia - a series of small strokes; and dementia with Lewy bodies - protein deposits on the nerve cells of the brain (Senanarong and Cummings, 2010). Although research increasingly focuses on the assets and potential of people with dementia, a diagnosis has traditionally led to deficit labelling with stigma, negative connotations and resulting low expectations from others (Graham, 2010). People with Down syndrome are at risk of most types of dementia, with Alzheimer's disease being the one most commonly experienced. Just as in the general population, people with Down syndrome may have more than one form of dementia concurrently.

1.3 Motivation for studying people with Down syndrome and dementia

The motivation for this research stems partly from my experience as Director of an intellectual disability organisation in Scotland, (referred to as Alba). This was a single condition organisation, the subject of criticism from within the disability movement, as will be discussed in Chapter Three. During my ten-year period as Director, from 1997–2007, the number of calls to the helpline, and emails received through the website, relating to dementia in people with Down syndrome noticeably increased. Calls were from parents, siblings and professionals within the UK and overseas. After completing an MSc in Dementia Studies, I was able to increase my awareness of dementia in the general population and apply this to people with Down syndrome.

Personal motivation was strong; my great aunt had Down syndrome and, unusually in the mid twentieth century, lived in the family home until her death in her forties. This highlights for me the change in attitude towards people with intellectual disabilities generally, in that greater life expectancy is now the norm rather than the exception. We still know so little about what people with Down syndrome want and need when they experience a progressive condition such as dementia. Given my interest in this field it is perhaps no surprise that the main focus in Stage Two is on the experience of people with Down syndrome themselves. It was important to me that having Down syndrome and dementia was the key criteria for inclusion in Stage Two; typically this has led to the exclusion of this group from research projects with our limited understanding arising from research with carers. Having explained why my interest lies in this area, I will now introduce my overall research aim and research questions for Stages One and Two of the research.

1.4 Research aim and questions

My initial aim was to understand the lived experiences of people with Down syndrome and dementia from their own perspective. This became complicated by the participant's lack of information about their diagnosis of dementia. It led me to shift my notion of 'understanding' to an understanding of factors that impacted on experience based on my observation, rather than claim that I had insight into the participant's understanding of dementia. Without an existing body of literature from

which to develop research questions, my two staged mixed method approach was developed based on the following questions:

- What awareness do carers have of the early signs of dementia in people with Down syndrome and what action was taken post-diagnosis? (Stage One).
- What factors impact on the experience of people with Down syndrome and dementia? (Stage Two).

These were ambitious aims, particularly in Stage Two, as people with Down syndrome and dementia are not typically seen as major contributors to research. Indeed, it will be shown how traditional research methods did not lend themselves to the inclusion of participants who would experience changing cognition and communication. Instead, I developed a flexible, synthesised approach to both my methodology and methods of data collection which will be explained throughout this thesis.

Despite this early shift in direction, I maintained my original intention of only focusing on the person with Down syndrome in the second, more substantive, stage of my two-staged research, something that has not previously appeared in research literature. I took a phenomenological approach where explanation is sought from the meaning of those being studied (Peterson, 1997).

1.5 Structure of thesis

In Chapter One, I have provided a brief introduction to locate my interest. The research aim and questions have been presented to explain the two-staged approach, firstly involving family carers and staff to provide context, and secondly placing people with Down syndrome and dementia at the centre.

In Chapter Two, I give an overview of literature on the changes experienced over time by people with an intellectual disability, people with dementia and people with Down syndrome and dementia. The inclusion of literature about people with an intellectual disability and with dementia is due to the scarcity of literature focusing on Down syndrome and dementia. The social model of disability is a recurring theme in the literature for people with an intellectual disability generally, yet not for people with Down syndrome and dementia. I consider this as part of my discussion around understanding the experience of all three groups. This led me to identify factors in literature that suggested the potential for further marginalisation of people with Down syndrome after a diagnosis of dementia.

Chapter Three records the positivist approach taken to understand early signs of dementia, and actions taken by carers in the lives of people with Down syndrome and dementia. I explain the development of the questionnaire, access, sample, ethical issues, and method of data collection. Findings are presented and discussed in this chapter to give an overview of experience from a carers' perspective and to explain my rationale for the development of the research question for Stage Two of the research.

Chapter Four highlights the tension between reconciling academic rigor with using flexible research methods when researching real life experiences. I discuss the phenomenological approach adopted as my underpinning methodology. In doing so, I expand on the concepts of Husserl (1999) to consider the application of this approach, with associated difficulties, to my research.

Chapter Five explains my methods of data collection, taking a flexible approach that incorporated observation, pictorial documentation, informal conversation, and field notes. I explain my process of analysis as the identification of emerging themes from my transcribed data in order to develop case studies, followed by cross case comparison of the three case studies to highlight commonality in experience.

Chapter Six presents data collected during three years of one-to-one visits, interaction with, and observation of, three participants. In each case study, I present the findings that shaped individual experience:

- Case study A: Andrew lived in his own flat with outreach support provided by an intellectual disability specific housing association.
- Case study B: Lucy lived in an intellectual disability shared group home.
- Case study C: Hannah lived in a generic care home for older people.

Discussion in Chapter Seven moves from individual case descriptions to cross case comparison as I present commonality in experience that emerged thematically from the three case studies. This highlights issues that have impacted on experience:

discourse over the lack of a shared diagnosis, evidence of a sense of Self among participants, the importance of relationships, adapted communication methods and the role of staff. I discuss these issues in relation to the continued process of marginalisation of participants both socially and culturally.

Chapter Eight summarises my findings to show how the experience of people with Down syndrome is of further marginalisation after a diagnosis of dementia. In identifying the exceptional experiences for this group, I consider how far I can reconcile potentially adding to the existing negative stereotype by recommending specialist services.

As a professional working in this area for many years I felt equipped and confident to meet, communicate and engage with people who had Down syndrome and dementia. I was not prepared for the emotional attachment to the three participants in Stage Two, nor my feelings of helplessness and, at times, distress at my observations during the research period. Given the lack of published research, and with a starting point of challenging the lack of previous inclusion in research for this group, I began my research by, separately, examining literature related to people with an intellectual disability, dementia and Down syndrome and dementia, firstly giving an overview of changes experienced both historically and socially. This is now presented in Chapter Two.

CHAPTER 2

UNDERSTANDING EXPERIENCES: EMPIRICAL AND THEORETICAL PERSPECTIVES FROM LITERATURE

2.1 Introduction

A major contribution of this research is the inclusion of people from a typically excluded group who have previously been absent from research literature. This chapter explores why this may be the case, as I consider the limited body of empirical and theoretical literature that informs of the understanding of experience of people with Down syndrome and dementia. After explaining my search strategy, the first section in this chapter presents a historical overview of changes experienced by people with an intellectual disability, people with dementia and people with Down syndrome and dementia. The second section considers the changes in support and subsequent social interaction of all three groups. This highlights a conceptual issue in that the social model, although viewed differently in relation to each group, has not been fully applied to people with Down syndrome and dementia. Finally, I consider the process of marginalisation and the way in which people with Down syndrome and dementia are marginalised at social and cultural levels. From birth some people with Down syndrome will have been viewed as marginalised; an automatic response from others to their situation (Kagan, 1995). Not so for a person with dementia who

may become marginalised for the first time in later life after their diagnosis of dementia.

2.2 Search strategy

Although this research took place in Scotland, literature is included from around the English-speaking world. I widened my review to include international research early in the process due to the paucity of published information on Down syndrome and dementia in the UK. As a result, the research is predominantly from societies where there are ageing populations. The literature review was initially conducted from 2006-2007. As I wanted to trace how support had developed, I removed dates from my literature search in order to get a historical overview. This was revisited in 2010-2011 by adapting the search dates to ensure the inclusion of articles published since 2007.

I used the online libraries of my employers during the research period to search and regularly read online journals. A review of literature was conducted indexed in Medline, ISI Web of Science, Cinahl and PsychINFO. My inclusion on email lists from publishers in health and social care alerted me to new journal articles and books. I conducted searches beginning with the term ‘history of people with intellectual disability/learning disability’ and ‘experience of people with intellectual disability/learning disability’ to narrow down the original 20,000 plus articles to a more manageable total of 225. This was done by narrowing the age range in the search criteria to adults and removing articles about: clinical or medical trials,

specific health conditions such as epilepsy, obesity and depression, offenders with an intellectual disability, and grey literature including conference reports. The same process was followed with dementia articles where the removal of trials, depression, non UK, and specific types of dementia or dementia-related illnesses, left me with 301 articles. Not all are included in this thesis due to some replication of content and research topic. The literature on people with Down syndrome and dementia after removing duplication, clinical studies and associated health conditions left me with 97 articles to review, with a further 13 added after my 2010-2011 search.

I remained aware of the risk of categorising the participants as service users, due to much of the available literature doing so. Most published research is about what is 'done to' a social care client as part of service delivery, whether they have an intellectual disability or dementia. As part of my literature search I used the terms 'person with' and 'individual with' as I wished to include literature that focused on the person, in addition to only searching for 'dementia' and 'learning disability' or 'intellectual disability', which may have resulted in a more medical reading list.

From the outset, I was clear that I did not view dementia only as a medical condition with 'sufferers', a negative term implying a victim. Throughout the thesis, I use the terms 'intellectual disability' and 'Down syndrome' consistent with the terms used within an international health and social care context, although during my literature search the terms 'learning disability', 'learning difficulty' and 'Down's syndrome' were all used.

This preferred terminology of ‘people with an intellectual disability’ is contrary to Shakespeare’s (2006) belief that the term ‘people with’ in the context of ‘people with disabilities’ implies individual deficits and is reflective of the medical model of disability. Shakespeare, and others, prefer ‘disabled people’ and hold the view that people with a physical disability are impaired by society. My approach is consistent with the preference among organisations supporting people with an intellectual disability, to place the ‘person first’, as someone who also happens to have an intellectual disability. This is consistent with Kitwood’s (1997) reference to ‘people with dementia’. The exception to this is when I am directly referring to the work of authors of literature about physical disability, when I use their preferred language of ‘disabled people’. This is an early indication of the divergence in approaches and interpretation between the physical disability and intellectual disability movements.

2.3 Historical overview

As part of the process of understanding different experience, this review now gives an overview of how knowledge and discourse, or communication, have changed over time when considering changes in experience, first historically and secondly socially, of people with an intellectual disability, people with dementia and people with Down syndrome and dementia. I begin by focusing on people with an intellectual disability.

2.3.1 Historical overview of people with an intellectual disability

What we know today can, for many people with an intellectual disability, be traced to their background in institutions excluded by, and from, society. For many, this was with a limited life expectancy due to routine lack of medical interventions and a lack of opportunities (Atkinson and Walmsley, 2010). It was the introduction of the National Health Service in 1946 that saw the change of such institutions into long-stay hospitals for people with an intellectual disability (Webb, 2002). After this period, accommodation evolved to smaller community-based settings. Developments over time have led to the potential for a more person-centred; defined by Curtin (1979) as looking from the person's perspective and supporting people as individuals, despite the potential for increased isolation if health needs change.

Our knowledge of individual experiences in long-stay institutions often comes retrospectively. This early emphasis on proxy and secondary data began a research tradition with people with an intellectual disability that was to continue for many decades. This includes reliance on medical records of the time and, more recently, researchers talking to staff and former residents. It has served to emphasise dominant relationships where professionals were afforded more control and choice than people with an intellectual disability. Having its roots in child care, and particularly adoption (Ryan and Walker, 1993), life story work is a more recent phenomenon as part of including people who have an intellectual disability in research. It usually relies on verbal participation (Hussain and Raczka, 1997), thus often excluding those with more complex disabilities. Similarly self-advocacy and inclusion is increasingly

sought with the phrase ‘not about us without us’ becoming commonplace; a phrase first heard among the physical disability movement (Charlton, 1989). Literature reflects the lesser extent to which this has been evident among those with more profound or complex intellectual disabilities (Walmsley and Johnson, 2003).

Traditionally, both children and adults in Scotland and the UK have called a range of different institutions home. Oswin’s (1973) work ‘The Empty Hours’ was seminal in highlighting neglect and inadequate care. As a result, this brought about changes to residential care and inclusion in education for children with intellectual disabilities. One of the hospitals included in Oswin’s research told of children being taken to queue routinely at the toilet before a meal. Nurses’ primary duties were domestic and functional, staff spoke to each other across the children when feeding them or encouraged the researcher to feed one of the children because ‘I don’t want to do him’ (Oswin, 1973, p.83). The television was on constantly as background noise and there were no attempts made to communicate with those children who had profound disabilities. Alongside this, a high turnover of staff was evident with many not speaking English.

Whilst practice has changed for those supporting children with a physical or intellectual disability, the same approach was allowed to remain longer in institutions for adults. It was not until 2000 in Scotland that ‘The Same as You?’ (Scottish Executive, 2000), a review of services for people with an intellectual disability, specified that people’s homes should not be in hospitals and that people with an intellectual disability should live in their own home for as long as possible. This was

in a context of increasing vocalisation among disability rights groups against institutionalisation, a movement that had been growing throughout the 1980s and 1990s (Oliver, 1996). This change did not happen at the same rate for people with an intellectual disability. 'The Same as You?' (2000) recommended that services must be inclusive of people with an intellectual disability and should be designed with individual needs as central.

Early resettlement programmes from long-stay hospitals across the UK began in the 1980s and saw responsibility for care transferred from the NHS to local authorities, although it was 2005 before the last institution closed its doors in Scotland. Previous learned behaviour was apparent among former residents of the long-stay hospitals. It became evident that some had attempted to minimise their marginalised status as, despite being on the margins of society, they had changed their behaviour in order to 'fit in' with their surroundings and behave as expected by staff, referred to by Wright and Digby (1996) as devaluing their sense of identity.

Following this period there was more of a move towards independent living; increasingly viewed as something to strive for by people with intellectual disabilities and their families (Walker and Walker, 1996). This saw the development of dispersed intellectual disability group homes, at first larger, then smaller and single person accommodation. Such moves were considered by Mansell and Ericsson (1996) to be the most significant post-war development for people with an intellectual disability. A package of care was often tied up with accommodation,

either on a 24-hour basis or with outreach support as required. Clustered or community housing also emerged with a number of houses on the same site.

It has been shown that, despite changes in society over time and increased inclusion for some, it was not enough for people with an intellectual disability to be physically included in communities. Without knowledge of individual experiences and an understanding of unique histories, it still remains possible for others to distance themselves socially and emotionally. The historical context of people with dementia will now be examined.

2.3.2 Historical overview of people with dementia

For people with dementia the move to community-based services was slower than for people with an intellectual disability. Whilst someone may already experience a degree of social exclusion from others on the basis of age, dementia adds a further layer to this due to the stigma associated with the condition, and its progressive nature leading to gradual incapacity. As with people who have an intellectual disability, there has been an increase in the self-advocacy role for some people with dementia as a way of raising awareness of their condition and experiences.

Consistent with research with people who had an intellectual disability pre-1980s, the language and terminology used when referring to dementia was stigmatising, and is now seen as outdated. Dementia was rarely referred to in policy or in guidance for practice. Research into dementia among older people initially focused on previous

neglect in institutions rather than planning for community living or understanding the experiences of people with dementia or carers. It was during the late 1980s that the term 'informal carer' was first introduced (Pitkeathley, 1989, p.37) recognising that most people with dementia were remaining at home for longer, thus acknowledging the role of family carers. A natural consequence of this growth of community care was an increase, and change, in areas of research with older people. More social research developed about experiences of living in the community although long-term care in an acute hospital setting still remained, where the dominant medical paradigm was evident (Marshall and Archibald, 1998).

The 1990s, with its mixed economy of care, saw a wider range of care providers for older people. This included a continuation of home care, where the majority of people with dementia lived, along with the development of an assessment of individual need for the person with dementia. The volume of research with carers of people with dementia simultaneously increased. This was usually conducted with a spouse or adult child, as a result of their increased recognised role as care providers (Barnes, 1997; Twigg and Aitkin, 1994). Devolution of care to the Scottish Executive in 1999 led to different initiatives being supported in Scotland to those in England, Northern Ireland and Wales.

With diagnosis later in life the older person is often in a relationship with a spouse who, due to the nature of their relationship, becomes the main carer. Alternatively, an adult son or daughter will often take over a caring role. For those who move to a care home, Brown-Wilson (2008) noted that, even if basic standards of care and

knowledge were evident, what was missing among staff were skills in interaction and kindness in their day-to-day care of people with dementia. The researchers perceived that, despite moves away from institutional living, this still reflected an overall negative experience for residents. A common theme running throughout guidance for those supporting people with dementia is the need to ensure that support is provided to enable them to remain in the home of their choice (NHS Scotland, 2003).

This section has highlighted a different context with some consistency among people with dementia living at home or moving to a care home, albeit not the large institutions seen previously. The main change has been a more recent focus on giving choice to the person with dementia, with inclusion in future planning now demanded (Scottish Government, 2010). I will now consider what looking at their historical context can tell us about people with Down syndrome and dementia.

2.3.3 Historical overview of people with Down syndrome and dementia

Research literature about people with Down syndrome and dementia has been slower to materialise, giving less of a historical overview and far less of an understanding of experience. This is despite the emerging link between Down syndrome and dementia being recorded in the 1970s in medical journals (Burger and Vogel, 1973). This section will consider how early knowledge developed into the policy and practice picture currently seen to support people with Down syndrome and dementia. It takes into account the pre-existing social exclusion due to having an intellectual disability

plus the added ‘double whammy’ (Williamson, 2009, p.6) of a diagnosis of dementia. There is little acknowledgement in policy that not everyone with dementia is an older person, nor that before a diagnosis of dementia an individual may already be living with reduced cognitive abilities and different communication strategies. Research suggests that formal and family carers of people with Down syndrome may not be aware of recommendations for providing support after a diagnosis of dementia (Courtenay et al., 2010), leading to a greater potential for misinformed decisions post-diagnosis. This includes sharing information about the diagnosis in an informed and appropriate manner, as is recommended for older people with dementia.

A model of care seen in literature about accommodation options (Janicki and Dalton, 1999) is referral out, ageing in place and in place progression. Referral out involves a move for the person with an intellectual disability to a generic social care environment or, if health needs are prominent, to a nurse-led facility such as a nursing home. Thompson and Wright (2001) noted the frequent inappropriate placement and referral out of people with intellectual disabilities into older people’s services. In Scotland, approximately 1,000 people with intellectual disabilities are believed to live in residential care homes, some aged under thirty, with a third reported to be aged under fifty-five (Learning Disability Alliance Scotland, 2010).

Ageing in place refers to a person with an intellectual disability and dementia remaining in their own home environment, with adaptations, after a diagnosis of dementia. This includes incorporating staff training in dementia into service provision and environmental adaptations, to minimise the effects of dementia on the

person and on others living in the same accommodation. Many people in the UK age in place in intellectual disability group homes. This is likely to be somewhere they have lived for many years. Despite this being the place where they may be known best, it has been shown to result in areas of difficulty after a diagnosis of dementia. For example, concern was raised by other residents with an intellectual disability in group homes that the person with dementia was seen as having 'special privileges' if they were treated differently by staff (Forbat and Wilkinson, 2008, p.7). Resentment was apparent if changes, or environmental adaptations, which are recommended in dementia care, were made to their shared home. The resident who had dementia showed little or no awareness of having dementia or what this implied; conversely the impact was strong on their peers in the group home (Wilkinson et al., 2004).

The third option in Janicki and Dalton's model for people with Down syndrome and dementia is in place progression (Janicki and Dalton, 1999). This refers to a move to, or creation of, a dementia-specific environment for people with an intellectual disability. Those with broadly similar levels of need are provided with a range of accommodation options and support in a specialised setting. It allows for progression through stages of dementia whilst the person stays in the same environment.

Llewellyn (2011) wrote that prioritising the lead service was crucial in meeting the needs of people with Down syndrome and dementia. She noted a consensus in research that it should be intellectual disability, rather than dementia care services for older people who take the lead in provision of support for people with Down syndrome and dementia. Whilst we know about the locations of care, we have some way to go to understand experiences within these care settings.

This section has shown that much literature has been based on where people live as part of changing models of care. The opinions, preferences and experiences of individuals with an intellectual disability and people with dementia are increasingly being heard. The same cannot be said about our understanding of the experiences of people with Down syndrome and dementia, or those with other complex needs. Just as the availability of literature varies between the three groups when looking at the historical context, the same applies when seeking to understand what literature tells us about the support available and social interactions with others.

2.4 Development of support

2.4.1 Social support of people with an intellectual disability

How confident, or empowered, a person is made to feel by others will contribute to their ability to share experiences. A range of strategies and approaches have emerged that will be explored to determine how far they help to reduce the social exclusion of people with an intellectual disability. The first to be considered is normalisation which introduced a set of principles that stressed the importance of changing services so that people with an intellectual disability were able to live in ordinary places, doing ordinary things with ordinary people (Wolfensberger 1972), essentially ‘being normalised’.

Not without its critics (Chappell et al., 2001), it has been claimed that normalisation was about the views of services, rather than the views of people with an intellectual disability, and that the movement did not acknowledge this power imbalance.

Culham and Nind (2003, p.71) referred to the 'denial of difference', as the emphasis was on conforming to society's norms rather than valuing difference. Despite criticism, this period reflected a time of change in approach to supporting people with an intellectual disability that had not been seen previously.

Person-centred planning for a person with an intellectual disability, originating from North America (O'Brien, 2000), has developed in many guises. Examples include personalisation seen, for example, through self-directed support and independent living; approaches intended to support people in planning their own lives. Both are based on the social justice principles (Emerson et al., 2009) that if people are to contribute on an equal basis, they need to be afforded choice and control over the support that they receive. Barnes and Prior (2009) noted that such changes provide opportunities to engage with processes that many had previously been excluded from. O'Brien (1987) prioritised community presence, choice, opportunities and participation in mainstream activities. He noted that people became more effective participants with the support of others and by sharing commonality in experience.

Bogdan and Taylor (1976) looked at relationships between a person with an intellectual disability and others, to consider the positive or negative stereotypes, or standardised images, that were held of that person. They saw that family carers, and long-term formal carers, were more able to recognise the individuality of the person,

instead of only seeing the disability. Balandin (2011) argues that rather than trying to normalise behaviours among people with a profound or complex disability, individuality and differences should be valued within relationships. Without this, there will be a lack of genuine understanding of experiences. Choice or preference was distinguished by Antaki et al. (2009) as life choices or daily activity choices, with the latter being more functional. They found that in residential services for people with an intellectual disability, choice often reflected management objectives rather than individual preferences. There is a general consensus that how far a person is included in decision making is dependent on what carers consider their level of disability to be, and how much autonomy that person is given by others (Jingree and Finlay, 2008). As with previous sections, this suggests a reliance on the intervention, actions or support of others to enable preferences, needs or experiences to be understood.

The issue of staff instigation needed to support and maintain friendships is a recurring theme in research literature (Cummins and Lau, 2003). This need for friendship is recognised as important universally, although is often ignored for people with an intellectual disability (Duvdevany and Arar, 2004). Alternatively, an assumption is made that friendships will happen automatically as a result of community inclusion. Relationships are rated as highly important by people with an intellectual disability where friendships are recognised as a strong indicator of quality of life. Despite this, the support and intervention needed by others to maintain friendships is often lacking (Cummins and Lau, 2003). Stewart (2009) suggests that the role of carers in maintaining friendships is unrecognised, yet essential, in

reducing high levels of loneliness and associated exclusion. Research literature supports the choice to socialise with others who also have an intellectual disability, despite suggestions that this should be viewed as negative and against the principles of normalisation (Stewart, 2009). This choice is often not recognised as a conscious decision (Bond and Hurst, 2010).

Today, choice is often assumed to mean opportunity for inclusion (Hammel et al., 2008). Myers et al. (2010) wrote that the difference between physical and social inclusion is often not recognised. Steps towards greater inclusion have involved listening to what is important to a person and acting upon this. Gillman et al, (2010) note the importance of understanding the unique experiences of people with intellectual disabilities to prevent professions from further distancing themselves. For people with an intellectual disability, this has included the development of tools such as Personal Futures Planning (O'Brien and O'Brien, 2004). This is a process of getting to know an individual and recording their wishes, often pictorially. Essential Lifestyle Planning also developed from a person-centred planning approach. This is a method of learning how someone wants to live their life and developing strategies to make it happen. MAPS (Making Action Plans) support integration via a series of visual steps that highlight dreams and fears. PATHS (Planning Alternative Tomorrows with Hope), is a planning tool that starts in the future and works backwards (Forest et al., 2007), taking individuals' dreams and putting them into practice based on identifying goals and targets. A greater degree of self-advocacy is now seen where individuals and groups of people with an intellectual disability speak out for themselves. This signals a different approach for those who are able to set

their own agenda, for example the People First self-advocacy group in the UK.

Gilmartin and Slevin (2010) reported that this led to a greater sense of empowerment for the individual involved. As Barnes and Prior (2009) noted, this is not always in a proactive sense and at times is in response to a specific issue or change in provision. They challenge the notion of real partnership which will only be seen if service providers have more resources and influence, in addition to controlling access to services. Williams (2012) identified the contradiction in reducing budgets combined with an increased emphasis on co-production and the difficulty in managing personal budgets.

For those with more complex intellectual disabilities, differences and separation remain apparent as there is a greater degree of discrimination and exclusion (Blood and Bamford, 2010). Whilst there has been progression towards greater understanding of the experiences of some with an intellectual disability, it is clear that barriers and negative attitudes remain for others. The insight gained from literature about the experience of people with dementia will now be explored to determine if the same pattern exists.

2.4.2 Social support of people with dementia

Cohen-Mansfield et al. (2006) researched the sense of identity among people with dementia in relation to understanding their experience. They highlighted that understanding of a person's sense of identity decreased as dementia progressed despite Askham et al. (2007) recording that people with dementia became distressed

if their previous identities were not acknowledged. Their research suggests that people with dementia prefer to remain in existing family relationships and social settings. This enables individuals to create, and keep, meaning and identity in their lives by maintaining contacts and social relationships.

Increasingly, self-reports by people with dementia show that perception of their own health is accurate, even with declining cognitive skills (Sands et al., 2003). Banerjee et al. (2009) wrote that a lower cognitive ability in a person with dementia is not linked to them experiencing less of a quality of life. Other research suggests that feelings of the person with dementia are likely to be around their own morale and sense of wellbeing, whilst carers focus more on practical care issues (Hancock et al., 2003).

An example of research that sought the emotions of people with dementia is the use of doll therapy, a controversial approach to working with dementia (James, et al., 2006). This involves using a doll as a therapeutic tool to relate to the person's previous experience. For example, someone who believes that they are considerably younger due to the prevalence of their long-term memory can be reassured and calmed by the presence of a doll and its association with children. This approach is not without its critics (James et al., 2006), although the majority of criticism comes from carers due to perceptions around the use of dolls with an adult. This is an example of the prevalence of the views of others being considered rather than the potential benefits, or improved sense of well-being, felt by the person with dementia.

Diagnosis is seen as the starting point for other interventions, both medical and social. The National Institute for Health and Clinical Excellence (NICE) guidelines (2006) state that only in exceptional circumstances should information about a diagnosis of dementia be withheld from someone. Instead, discussion should take place early after diagnosis to enable the person to be involved with future planning in advance of changes in their capacity and ability to communicate. Research opinion regarding the sharing of a diagnosis of dementia with the older person continues to be divided. Debates around whether to share a diagnosis include a consequentialist argument that diagnosis should be given only if it will be of more benefit to the patient than not sharing the information (Brodaty et al., 2003). This includes the notion that sharing the diagnosis may increase the feeling of stigma experienced, especially in the early stages when people will be aware of the implications of the diagnosis (Marzinsky, 2000). It is perhaps less surprising that there is reluctance to share a diagnosis of dementia as there is not the same outlook, or prospect of positive treatment available with other conditions (Keightley and Mitchell, 2004). The decision over whether it will be of benefit is still made by professionals, although there is a consensus that carers should be as informed as possible (Hubbard et al., 2009).

Shamail et al. (2010) found that general practitioners (GPs) were not always convinced of the importance of an early diagnosis due to the lack of follow-up specialist support. Studies suggest that the diagnosis of dementia is not given effectively and that carers often do not want their family member to be told (Pucci et al., 2003). Woods and Pratt (2005) noted that even when a diagnosis was given to the

person with dementia it was more likely to be a euphemism, such as 'memory loss'.

The most common reason for giving a diagnosis is that the person wanted to know (Hubbard et al., 2009). Most were aware that changes were being experienced and wanted to know why.

The argument used in intellectual disability services, that it may cause further distress to the person if they are given their diagnosis, has been refuted in the general population. Carpenter et al. (2008) found no increase in depression and instead identified a reduction in anxiety after an explanation had been given for the changes being experienced. Despite this, and most guidance advocating that a diagnosis be given, many clinicians are still reluctant to do so, as few as forty per cent in a study by Pinner and Bouman (2002).

Kitwood's (1989) work gained prominence in dementia care with strong links being made between the person with dementia and their life history, life events and social relationships. Before this, the emphasis had been on bringing the person with dementia to our sense of reality. Kitwood developed this into a more person-centred approach focusing on the individual and their own sense of reality often based on their long-term memory, with this 'personhood', or individuality, seen as the basis for dementia care. His work challenged the dominant medical paradigm and emphasised the need for relationships, inclusion and interaction, thus promoting a move away from social exclusion. Kitwood (1997, p.17) argued that people with dementia are constantly at risk of 'depersonalisation' as a result of their personhood not being recognised by others. He saw disempowerment as a consequence of

depersonalisation, with a lack of recognition of the retained abilities of people with dementia by carers. In contrast, personhood and individuality may be maintained and supported with a nurturing relationship that acknowledges the need for comfort, attachment, identity and inclusion (Kitwood, 1997).

Hulko (2004, pg. 238) has more recently extended these concepts to introduce intersectionality, with a focus on the identity of individuals, highlighting the increasing amount of research that aims to understand the experience of people with dementia both individually and in relation to others. Hulko's work recognised the importance of knowing where each person is located socially within their different identities and within a broader environment. It acknowledges the role that family carers and staff have on how dementia is experienced. O'Connor et al. (2010) gave the example of relationships and knowledge of the diagnosis being crucial to the sense of well-being of the person with dementia. In other fields this has been developed further, for example Nolan et al. (2006) carried out research with student nurses and advocated for a 'senses framework' based on a relationship-centred approach. Stemming from research on chronic illness among older people, the 'senses' referred to the sense of purpose, achievement, security and belonging when creating an appropriate environment. The focus on a relationship-centred approach reflects a wider range of interactions including those with practitioners, family and community. Relationship-centred refers to the triad of the older person, their family and paid staff recognising the needs of all three. This does not fully take into account the situation whereby an individual with an intellectual disability may not have a

relationship with family members, nor where family members may have been the sole support with no previous involvement from professionals.

As part of attempting to understand experience, Sabat and Harre (1992) distinguish the 'person' with dementia, who is socially defined and publicly visible as distinguished, from the 'Self'; the individual with unique circumstances and personal history. This stresses the importance of relationships, autonomy and where people are placed in relation to those around them. Sabat (2002) recorded three types of 'Self', the first being 'I' or 'me'. Sabat suggests that Self 1 remains largely intact even in those with profound cognitive impairment. Self 2 involves a degree of insight into positive or negative attributes, for example 'I can do that' or 'I am not good at that' reflecting a sense of pride or frustration. Sabat also saw this as remaining intact in people with dementia, although it was potentially compromised by any additional disability that caused the carer to focus on the disability rather than the person. Self 3 is the way in which people present themselves socially in different contexts. It requires different behaviour in each setting and as a result Self 3 can be constructed through interaction with others. Other literature focuses on the importance of recognising the ability to maintain interaction with others, such as Hughes (2001) who emphasised the importance of engagement with the changing world around people with dementia. Hughes et al. (2006) later showed how the wellbeing and selfhood of people with dementia can be improved by focusing on their psychosocial environment. No studies have been carried out to show the level and scope of engagement by, and with, people with Down syndrome and dementia or how they perceive their sense of Self.

This section has demonstrated the same need for relationships as evidenced among people with an intellectual disability, with a greater sense of awareness among people with dementia than was often appreciated by carers. It has become evident that research including people with dementia has been primarily conducted when the participants were in the early stages of the condition and had verbal capacity. This is when we hear more from the perspective of the person about their experiences, whereas the later stages focus on carer perspectives. People with dementia and carers, such as the Scottish Dementia Working Group (SDWG, 2012), are increasing being supported to take on a self-advocacy role, by highlighting their own experiences and priorities and making recommendations for national priorities. This is not reflected in the wider population where literature still reflects the low status afforded to people with dementia and carers. However, we do know more about the support of people with an intellectual disability and of people with dementia than of individuals with Down syndrome and dementia, as will now be discussed.

2.4.3 Social support of people with Down syndrome and dementia

There are increasing amounts of information, literature, practice and even dedicated staff members to support younger people, aged under sixty-five, with dementia in the general population. Most research literature and policy only includes a statement that people with Down syndrome are at risk of developing dementia at a younger age. As a result, it should not be a surprise that there remains a mystique around the most appropriate way to provide support to this group, and personal experiences of individuals with Down syndrome and dementia remain unheard.

During the period when normalisation was gaining prominence among people with an intellectual disability, social research into people with Down syndrome and dementia began to emerge. This largely focused on the perspective of the family carer (Prasher and Filer, 1995) as the majority of people with Down syndrome were, by this time in the 1990s, growing up in the family home. Research was centred on the age of people at onset, the rate of progression and the difficulties that became evident when dementia was diagnosed. This included changes in behaviour (Prasher and Filer, 1995), changes in speech (Cooper and Prasher, 1998) and changes in physical condition with increased likelihood of, for example, epilepsy in the later stages (Palop, 2009). Whilst this early research provided important information to help understand the link between Down syndrome and dementia, it was not inclusive of people with Down syndrome, nor did it give insight into their experiences.

We know more of the views of people who share accommodation with a person with Down syndrome and dementia, and the views of others such as formal and family carers rather than the views of individual with Down syndrome and dementia. Brown and Brown (2005) noted that research including people with Down syndrome and dementia should start from the same premise that everyone has the same basic needs, and that a sense of well-being can be improved by empowerment gained by taking part in decisions affecting them. Evidence of this happening is not widely visible in research literature. Lloyd et al. (2007) researched life satisfaction and ideas about the future among people with Down syndrome and dementia, although participants were able to verbalise their answers. This suggests that further study is needed with those for whom verbal communication is impaired, or has changed. Lloyd et al. (2007)

suggest that people with Down syndrome are unlikely to know that they have dementia, but will still be affected by the attitude of other people and will be aware that something is different.

The first, and so far only, research that has looked from the perspectives of people with Down syndrome and dementia was published in 2007 (Kalsy et al.). The research was carried out with people in the early stages of dementia using semi-structured interviews to find out the impact that a diagnosis of dementia had on each of the six participants. Themes common to those in older people with dementia were noted, such as awareness of declining skills, developing coping strategies, positive self-image and the ability to understand the emotional experience of participants. The researchers noted that how participants made sense of what was happening to them was complicated by their existing intellectual disability, rather than by their knowledge of dementia.

Professional reluctance to give a health diagnosis to an individual with an intellectual disability, or an older person with dementia, can be perceived as adding credibility to the decision not to disclose dementia to the person who also has Down syndrome. The importance of giving the diagnosis as an ongoing process (Bakker et al., 2010) is not recognised for this group. The development of a framework or practice guidelines for giving a diagnosis of dementia to a person with an intellectual disability has not been addressed in literature. This makes it impossible to find out about experience of dementia from an individual perspective, when the person with Down syndrome is not aware of their diagnosis.

There is an acknowledged need in policy to reduce the stigma associated with dementia (Department of Health, 2009). Whilst this may appear to be a compelling reason for not sharing the diagnosis with a person with Down syndrome, it does not fit with wider UK policy or guidance. The dementia strategies in England (Department of Health, 2009), Scotland (Scottish Government, 2010) and Northern Ireland (Department of Health, Social Services and Public Safety, 2011) state that everyone should be given their diagnosis. Although care and support for people with dementia were included generally in the strategies, it was not specific about those who also had an intellectual disability or younger people with dementia. This lack of clarity, and access to information, leaves a question about their relevance for people with different needs, who are much younger but who experience the same condition.

Increasingly, knowledge of issues affecting people with an intellectual disability is coming from the person themselves rather than a carer or proxy. People with an intellectual disability, as with people with dementia, have been supported or enabled to take part in research although with varying degrees of inclusion. In the intellectual disabilities field this maybe using a participatory approach which involves people being included as co-researcher; research is 'with' rather than 'on' (Kiernan, 1999; Chappell, 2000). An alternative approach is emancipatory research (Barnes and Mercer, 2003) where people with a disability take full control of the research process from the beginning. In the field of dementia, there are examples of an understanding of experiences and views (Pratt and Wilkinson, 2001) and also of seeking non-verbal methods of communication (Cook, 2003). An emancipatory approach is also seen with people with dementia recording their experiences, taking more control and

being far more engaged on the process. However, despite this continuum, participatory and emancipatory research are not synonymous with people who have profound or complex disabilities. Consequently, research remains largely exclusive of those who have degenerative cognitive difficulties, including people with Down syndrome and dementia.

Having considered the development of support and changes in experience over time in this chapter for people with an intellectual disability, people with dementia, and people with Down syndrome and dementia, I will now develop a common theme that has emerged; that of marginalisation. This is evident in all three groups at different levels and to varying degrees. I will then consider how far the social model, with its emphasis on combating labelling and stigma, has addressed this challenge.

2.5 Marginalisation

Williams (1998) defined social marginalisation as the process of individuals or groups being on the outside, on the margins, not able to contribute to society. This applies at both a societal level and also through individual interpersonal interactions (Walker and Walker, 1996) where it leads to stigma at local level. Stigma is the label associated with pre-conceived notions about an individual or group. If negative, this can result in the individual social identity being devalued (Crocker et al., 1998). Negative stereotyping and associated stigma lead to discrimination, which in turn creates a lack of access to service or basic human rights. For example, social marginalisation is based on differences which can lead to individual stereotyping,

meaning that minority groups are excluded from opportunities and find it hard to have a voice or to participate in their community.

Cultural marginalisation emerges after the development of practices that meet the needs of the majority rather than those of the marginalised group (Leonard, 1984). This means that wider cultural awareness is needed of experiences of people with Down syndrome, and people with dementia, before the stigma of having both Down syndrome and dementia can be challenged. Creating an effective culture for the provision of support for people with Down syndrome and dementia will rely on a common vision, often stemming from policy or legislation, through which values are then implemented and observed in practice (Johnsen, 2010). At the other extreme, this also has to be driven forward at an individual level by an understanding of the needs and experiences of people with Down syndrome and dementia. Without a wider cultural awareness, this group is at risk of becoming further marginalised at an individual level, suggesting an overlapping of these concepts of marginalisation. The disability rights movement is a strong advocate of reducing both marginalisation and stigma (Gill, 2001). To tackle stigma at an individual level is harder; it has been found in research to be more effective when cascaded down through policy (Sayce, 1998), and if backed up locally with training and direct contact with service users (Thornicroft, 2006). However, people with Down syndrome and dementia as a group, are not specifically included in policy that relates to either intellectual disability or dementia, although some areas have developed local or professional guidelines (British Psychological Society, 2009) reinforcing the potential for cultural

marginalisation. Sheppard (2006) identified key factors as needed to reduce marginalisation:

- if a sense of identity is understood in the person;
- how far attempts have been made to overcome any difficulties in communication;
- the extent to which someone is defined by their individual experience rather than their situation, or additional need;
- knowledge of the group in terms of statistics and incidence.

I will return to Sheppard's criteria when considering my research findings in Stage Two, as part of identifying factors that have impacted on the experience of people with Down syndrome and dementia, and will discuss them further here in relation to research literature. Despite having awareness of the link, literature does not provide accurate figures of the incidence of dementia in people with Down syndrome in the UK or internationally. This lack of data contributes to the lack of any perceived injustice for people with Down syndrome and dementia. Without this recognition as a group in social policy terms, it is not identified as a key issue, with potential created for further isolation and marginalisation.

General needs of people with dementia, those in common with others, remain overlooked (Innes et al., 2004). As people with Down syndrome already experience stigma due to their intellectual disability, there is potential for their additional needs relating to dementia to remain unmet if they are not understood, again leading to

wider discrimination and marginalisation. Decisions about the healthcare of a person with an intellectual disability continue to be made by professionals, reflecting a long-held dominant approach (Wong et al., 2000). Gillman et al. (2010) report that having an intellectual disability is often viewed by health professionals as defining the person's life. This results in a lack of response to individual need, leaving treatable conditions undetected. This diagnostic overshadowing is often referred to among people with an intellectual disability (NHS Scotland, 2004).

Further examples of people with an intellectual disability not being given a health diagnosis have been identified by Brown et al. (2010) and Tuffrey-Wijne (2009). Each noted differences to the general population when giving a diagnosis of cancer. The person with an intellectual disability was either not given the diagnosis, or was given false reassurances about their prognosis. Tuffrey-Wijne (2009, p.315) refers to the principle of 'no lying' as being needed, and that informing someone of their diagnosis needs to be a process rather than a one-off event. This would counteract any cognitive difficulty in understanding the information. Not sharing a health diagnosis with the person, or their carer, is commonplace for professionals in the belief that this would add to carer stress or burden, along with not wishing to cause distress to the patient (Mossello et al., 2008). This suggests the potential for people to be defined by their circumstances rather than by our understanding of their individual experiences. This marginalisation can manifest itself in the creation of the 'Other' and the 'Othered' in a relationship.

2.5.1 The concept of Othering

The Othering process is one that identifies those thought to be different from the mainstream in society. It can reinforce and reproduce positions of domination and subordination by creating social distance, marginalisation and exclusion. Weis (1995) wrote that Othering defines identity and sets up difference as a point of deviance, creating a 'them and us' scenario. The concept of the Other dates back to 1950s and feminist theory (de Beauvoir, 1952) and was referenced by Said (1979) in terms of colonial power and imperialism. It has been applied more recently to minority groups such as people with disabilities and immigrant groups (Weis 1995) with Williams (2012) writing that the term is generally used to describe the process of a disadvantaged group being viewed as different and subsequently excluded.

Hall (2005) wrote in a different context that Othering preventing people with disabilities from being seen as contributors to society. Consequently, when policy is formed and implemented, people with disabilities are not viewed as a key part of the process. This means that, for example, people with Down syndrome are removed from society by social policies that control areas such as housing, employment and transport, resulting in exclusion at societal levels for those who cannot independently access these areas. It demonstrates the importance of looking at populations as a whole, in addition to individual needs. This is consistent with Thornicroft's (2006) requirement of a 'top down' approach in order to incorporate the needs of marginalised groups into policy. With a diagnosis of dementia, there is a risk of people with Down syndrome being categorised with older people who have

dementia, regardless of obvious differences, such as disability and age. Fine (1994) witnessed this in research, giving the example of participants being 'Othered' by the research process if viewed as a homogenous group, rather than being valued for their individual contributions and experiences.

A further recurring theme in the literature review for people with an intellectual disability has been the social model of disability (Oliver, 1996). This has been evidenced through barriers created by others for all groups, leading to exclusion, and negative attitudes.

2.6 Social model of disability

The social model, with its origins in physical and sensory impairment, developed as an alternative way of understanding disability in the 1970s (UPIAS). It originally distinguished between impairment (a loss of functioning), and physical disability (how society views the impairment). Oliver (1996) viewed three elements as being necessary when determining the identity of a disabled person: the presence of impairment, the experience of externally imposed restrictions, and self-identification as a disabled person.

In the UK and Europe, the social model of disability has focused on removing social barriers and oppression. This challenged the view of a person with a disability as an individual who had something physically wrong with them (Swain and Griffiths, 2003). The traditional model saw a move away from individual limitations, and

instead saw a shift to thinking of disability as a condition of society in which people were discriminated against and marginalised. It saw an emphasis on promoting disability as having a positive sense of identity, rather than being a personal tragedy. Consequently, the social model saw a move from dependency to people taking greater control over their own lives and decisions.

As the original emphasis of the social model was on people with a physical disability, there has been little clarity over its relevance for people with an intellectual disability (Oliver and Barnes, 2009). Whilst it appeared to offer much in terms of change in attitude and opportunity, the social model has been argued by some (Goodley, 2001; Chappell, 2000) to have failed to materialise for those with intellectual disability. Instead, Chappell (2000) suggests that it has contributed to further marginalisation, as the most that can be achieved is that people with an intellectual disability are included in general writing about disability. Others argue that it is a lack of application of the social model to people with an intellectual disability that is more relevant than a failure of the model itself (Boxall and Ralph, 2009). Boxall and Ralph argued that rather than focusing on the increased marginalisation of people with an intellectual disability, the focus should be on ways in which individuals could be supported to contribute to discussions about the model and to document their own experiences. The same could be said of people with Down syndrome and dementia as attempts to do this have not been documented, particularly as dementia progresses, leaving this group with a silent voice.

Oliver (1996) maintained that if people share a common experience of disability, then impairment-specific organisations are unnecessary. Whilst working for a single-impairment organisation when beginning this research, I have seen how this does not necessarily mean that a progressive and relevant approach that encompasses both medical and social issues is not achievable. Shakespeare (2006) agreed with Finkelstein (2002) that impairment-specific organisations can address specific social and medical issues, although warned that too much fragmentation may result in less overall impact. Additionally, it offers a greater opportunity if we know how many people have a specific disability with associated benefits for future planning, something already identified as lacking in people with Down syndrome and dementia.

2.6.1 The social model of dementia

As part of the recognition that people with dementia should be viewed as individuals and experts in their own condition, there has been a call for dementia to be recognised as a disability and framed within the social model (Marshall, 1994). Taking the, perhaps limited, view that if the social model focuses on the barriers that people face when they are considered to have a form of impairment, then dementia may fit the definition. It emphasises the interaction between medical and social factors as dementia progresses, plus the importance of community and social networks. Despite an increasing range of research and literature involving people with dementia, little emphasis has been given to the social model since Marshall's statement. Blackman (2003) maintained that use of the social model de-medicalised

dementia. Certainly if dementia is to be constructed as a disability, then to fit the model it would be defined as a problem created by society in terms of environmental and social factors, rather than being an individual problem. This does not address Blackman's point that dementia remains a medical condition, although by linking the social model with dementia Marshall has perhaps opened the door to an approach that moves away from deficits towards assets. This would keep a focus on the skills retained by the person rather than those lost, with recognition given to a supportive environment, appropriate communication and an awareness of the background of each individual. Marshall (2005) maintains that whilst people with dementia may have a cognitive impairment, their disability arises from the way they are treated within, or excluded from, society. What her stance did achieve was to raise awareness of dementia as a condition requiring an understanding of individual experience.

In other conditions, notably chronic illness or cancer, the voice and shared experience of the patient has been instrumental in changing attitudes. This has not been so apparent among people with dementia. Whilst attitudes are shifting, Dorenlot (2005) maintains that things need to progress further before the social model can be applied to dementia, particularly when considering its progressive nature. Just as disability rights activists have been reluctant to embrace people with an intellectual disability as part of the social model, the same applies for people with dementia. Gilliard et al. (2005) felt that the social model of dementia may be more aptly applied to carers, and those providing support, rather than people with dementia themselves where they believe that the model has not been fully inclusive.

2.6.2 Relevance of the social model of disability for people with Down syndrome and dementia

Whilst literature about people with an intellectual disability is inconclusive about the relevance of the social model, it is even less convincing for people with Down syndrome and dementia. This reinforces Boxall et al.'s (2009) argument that rather than lack of relevance, it may be due to a lack of application. Drawing on the basic premise of the social model, the following general principles have been applied as a recommendation for practice with people with Down syndrome and dementia (Dodd, 2008):

- people are disabled by the way they are treated by or excluded from society;
- it is not the fault of the individual;
- the focus should be on remaining skills rather than losses;
- the person can be fully understood in terms of their preferences and history;
- a supportive environment is essential;
- appropriate communication is essential.

This approach reflects that seen among those with an intellectual disability generally, where the emphasis is on the person taking greater control of their own lives. It reinforces Blackman et al's. (2003) claim that applying the social model in its current form to people with dementia does not acknowledge the requirement for accompanying medical intervention, something not included in the above list. Nor

does it recognise the change in cognitive ability associated with dementia and the change required in support. People with Down syndrome and dementia have a combination of a pre-existing disability plus a progressive medical condition, reflecting the World Health Organisation International Classification of Functioning, Disability and Health (ICF) which measures health and disability at individual and population levels (WHO, 2010). Health is viewed in relation to physical, emotional and mental health rather than just in terms of an absence of disease. The ICF states that everyone will experience a degree of ill health, and as such will experience a degree of disability. By mainstreaming disability in this way, the ICF recognises disability as a human condition and takes social aspects into account, rather than only focusing on medical intervention. The World Health Organisation states that knowledge of a particular health condition does not predict functional status, as is often the reality after a diagnosis of dementia due to the associated stigma. My literature review has highlighted this need for both the social and medical model to be applied in a way that acknowledges the need for a cultural change through challenging current practice, and addresses the stigma associated with a diagnosis of dementia and the current lack of understanding of the experience of people with Down syndrome and dementia. This is not currently recognised in literature. Other gaps identified as part of this review are shown below.

2.7 Gaps in research literature

There is a correlation between the gaps identified in research literature about Down syndrome and dementia, and factors that have been identified in this section as contributing to social and cultural marginalisation.

- Accounts of people with Down syndrome and dementia from their own perspective, including how they perceive their sense of Self.
- Data reflecting the number of people with Down syndrome who are, or may in the future be, affected by dementia.
- The experiences of people with Down syndrome through the progression of dementia, if they are not aware of their diagnosis.
- Research with people with Down syndrome and dementia that includes two-way communication as verbal and cognitive ability continues to change.
- Discourse that blends key areas of knowledge from the fields of intellectual disability and of dementia, rather than each working in isolation.

It has been shown earlier that, based on available literature, these gaps typically differ from literature available about the experiences of people with an intellectual disability and people with dementia.

2.8 Summary

This chapter has presented the changes experienced over time by people with an intellectual disability, people with dementia and, to a lesser extent, people with Down syndrome and dementia. Empirical research has highlighted both the historical and social context for each group. This has shown the connection between adapting communication, recognition of sense of Self, and how the development of person-centred approaches over decades means that choice, control and independence are increasingly expected as an integral part of the lives of many people with an intellectual disability and people with dementia. Despite challenges around service delivery, this undoubtedly reflects an increased focus on individual experience.

A significant shift has been seen which means that long established patterns of physical exclusion have been challenged, with moves from large institutions to community-based provision. Yet, whether consciously or not, society is still willing to tolerate discrimination of those who are considered outside of the accepted norm (Kabeer, 2000). This particularly applies to those with complex or high support needs where many have been positioned as passive recipients of care, with little recorded opportunity for self-expression. This shows that we need a greater understanding of the combination of Down syndrome and dementia in order to address the extent to which people become further marginalised, socially and as part of wider cultural attitudes. Not being told of their diagnosis of dementia restricts the opportunity of people with Down syndrome to take part in decisions that affect their future support or health care needs, or to share their specific experiences of their

illness. This suggests that the social model of disability will be limited in application, with the lack of 'top down' recognition in policy contributing to cultural marginalisation, and a subsequent lack of interventions through training and models of support or service delivery. Consequently, there is a lack of emphasis on supporting an individual to understand and take control of their own situation, resulting in further social marginalisation. My thesis aim and Stage Two research question reflect this need to understand factors that impact on the experience of people with Down syndrome and dementia.

This review of the literature has led me to question some of the rationale for not seeking out the perceptions of people with Down syndrome and dementia earlier. It is particularly significant as we have known of the link between Down syndrome and dementia for a number of decades, and have witnessed the steps taken to reduce exclusion, and to adopt more person-centred approaches to support people who have either an intellectual disability or dementia. The literature review reaffirmed my aim to understand the experience of people with Down syndrome and dementia. This voice and experience is not evident in the way that the voice of people with intellectual disability or dementia has increasingly been heard. It has resulted in a Cinderella service that reflects our limited knowledge of the experience of this group.

The literature review reaffirmed the aims of this thesis a two-staged mixed method study. Stage One is presented in the following chapter with the aim of understanding the awareness carers had of the early signs of dementia in people with Down syndrome and identifying the action taken post-diagnosis. Use of a postal

questionnaire enabled me to begin with experiences from a carer's perspective; to set the context and gather information as I started the journey towards developing the more substantive second stage. Stage Two focused on people with Down syndrome themselves with the aim of identifying factors that impacted on the experience of people with Down syndrome and dementia.

Stage Two demonstrates a change from my original research aim, which was to understand the individual experience of dementia in people with Down syndrome. This subtle difference relied on the participant being aware that they had dementia. The reality proved to be different; Stage One highlighted the large number of carers who confirmed that the person they cared for was not aware of their diagnosis of dementia, or in some cases even that they were ill. All of those who volunteered for Stage Two were in this category. As a result I changed the focus of my research from 'understanding the experience of people with Down syndrome and dementia' to 'factors that impact on the experience of people with Down syndrome and dementia'. This enabled a more flexible approach to data collection and supported my use of case studies with an emphasis on observation, informal conversation or non-verbal communication and use of field notes. This shift in focus, and the lack of awareness of their diagnosis among the participants, raised ethical concerns which I return to in my methodology and methods chapters and again in my discussion in Chapter Eight.

CHAPTER THREE

STAGE 1 - POSTAL QUESTIONNAIRE

3.1 Introduction

This chapter presents Stage One of my research where I take a more objective stance, in contrast to my later subjective approach in Stage Two, I firstly discuss positivism as my methodological perspective and explain how this enabled me to gain understanding from carers. This was from the point of identifying early signs of the condition through to real, and potential, changes of accommodation as dementia progressed and care needs increased. Secondly, I discuss the rationale for my chosen method of a postal questionnaire and the process that I went through to gain access, develop content, collect and analyse the data. Thirdly, findings from Stage One are presented and discussed with an explanation of how this led to the more substantive Stage Two of the research, placing the person with Down syndrome at the centre.

3.2 A positivist approach

Positivism refers to knowledge about the social world that can be gained through scientific methodology (Saunders et al. 2007). This paradigm aims to generate explanations about how the social world of participants operates, in a way that does not interfere with the topic or phenomena under investigation (Levin, 1998). It seeks to explain relationships between variables following the collection of quantitative

data using pre-set questions. As a term, 'positivism' replaced earlier versions of positive science and positive philosophy (Crotty, 1998). Instead it refers to science, or knowledge, that is grounded in fact rather than assumed. In this way positivists are engaged with scientific observation carried out using scientific method.

Ontologically, positivists see reality as existing independently and as such it can be viewed objectively. I was aware that a key element of positivism was that results should be repeatable (Burrell and Morgan, 1979).

Faced with this definition, I had to question whether this would offer me the approach that I was looking for. This was due to positivism not taking account of subjective experience or feelings of the participants (Outhwaite, 2010). Carer experience was likely to change in the future and may have even changed since the person they cared for was diagnosed with dementia. It was possible that at a different time participants may have given a different answer, due to the different stages of caring for a person with dementia. This potentially removes a degree of objectivity as the research was not devoid of the social and historical context of each participant. I was aware of Goodley's (2001) criticism of positivist research with carers and professionals, due to its lack of inclusivity and lack of emphasis on the personal experience of people with intellectual disabilities. Similarly, Walmsley and Johnson's (2003) cite positivist research into IQ testing, and more recent research into 'challenging behaviour', as contributing to exclusion and leading to policies that are not based on the needs of people with an intellectual disability. Ward (1997) also maintained that inclusion in qualitative, rather than quantitative, research was essential to bring about empowering change and reduce marginalisation. However, in

such an under-researched area, I sought to firstly uncover a greater understanding of the issues affecting carers, a view supported by Alvermann and Mallozzi (2010). Whilst later in this thesis I move to the impact on individual experience, in this chapter I am more concerned with how carers responded and the actions taken. Positivist research is not entirely exclusive of people with an intellectual disability, as Griffin (2009) recorded when using quantitative research to measure well-being through exercise and weight management. However, I acknowledge that it is predominantly exclusive and remain aware of this criticism. I further acknowledge this in my thesis by not using the term ‘suffering’ as a key term in my literature search; a term stemming from early positivist research, again not based on the emotions of experiences of people with an intellectual disability (Oliver, 1998).

To a certain extent, I contaminated the research by having my own personal and professional viewpoint on this subject, something that I will discuss further in Chapter Four in relation to my decision to include phenomenology in Stage Two. Similarly, my viewpoint and knowledge was a crucial part in developing the postal questionnaire and whilst true objectivity may have been difficult to achieve, it was still possible to maintain a rigorous approach to design, data collection and analysis. The following sections explain this process, beginning with how I gained access to participants.

3.3 Access

This stage of the research began with a short advert in the newsletter of Alba, intellectual disability organisation. It invited family carers and paid staff to take part in a postal questionnaire to share information about dementia in the person they cared for with Down syndrome. An introductory letter (Appendix A) followed, if a willingness to take part was indicated, followed by a structured postal questionnaire (Appendix B).

The initial access to its membership of over a thousand carers, professionals and people with an intellectual disability was authorised by the executive committee of Alba. The article informed members that I wished to investigate the views of formal and family carers about dementia. Only members of Alba were able to take part, rather than requesting participants from members of other organisations. Whilst this reduced the potential range of participants, and may have been something that I needed to do had there been no response, it ensured that all respondents would be caring for a person with Down syndrome. Ideally, members of Alba who were known to be in this situation would have been individually invited, but this information was not known. For this reason, a short piece about the research was included in the newsletter requesting participants from the membership.

3.4 Sample

My intention was to first sample the larger group of carers in Stage One and from this group to request access to a smaller sample of people with Down syndrome in Stage Two. At this point I was aware of the lack of existing research on which to base my choice of method in Stage Two. This meant that the overall sample was multi-clustered with the membership of Alba being the initial cluster (Babbie, 2007). This is often used when either a complete list of potential participants is not available, or it would not be appropriate to contact the wider group or organisation. It was not appropriate to randomly select from the whole membership as many family members cared for younger children. This would have been inappropriate in terms of giving information about dementia. Those who requested information were advised that there was an optional second stage to the research that could involve the person they cared for.

The respondents were all family carers or paid staff who read the organisational newsletter. The article stated that I was seeking participants who had been caring for an individual with Down syndrome and dementia for five years or less. I was aware that each carer would be in a different situation, having had knowledge of the diagnosis for differing periods of time. Whilst I accept that this may make generalisation difficult, I was primarily seeking information on which to base, and set the context for, Stage Two of the research and felt confident that such an approach would enable this. No restrictions were put on the age, ethnicity or gender of carers.

The introductory letter and postal questionnaire were subsequently sent to forty-five carers; thirty formal and fifteen family carers. More were sent to formal carers which was representative of the membership of Alba where there were a higher number of formal carers among the membership. Although more family carers made use of the literature, resources and the telephone helpline, less actually took up membership. Response to the questionnaire reflected the gendered nature of the caring roles, both family and formal. This meant a higher number of female participants with a 1:3 reply ratio male to female in Stage One.

3.5 Ethical issues

I remained aware of ethical issues relating to the use of a postal questionnaire. As access to participants was via Alba, I realised that this may have influenced some people's decision to take part. Some may have preferred not to be involved for fear of not remaining anonymous. Others may have chosen to take part for this very reason, because they knew me, rather than because they actually wanted to be involved. I sought to minimise the risks by offering to maintain confidentiality. One aspect of being known to the participants was that they were able to contact me if they had any concerns or questions arising as a result of the questionnaire. Had this happened, it would be unlikely that I would have been able to include that person as part of the overall response. I would have potentially provided information that the carer may then take as their own and subsequently include as part of their response. In reality, this issue did not arise, therefore was not a concern, although I was prepared for the eventuality. By recognising the importance of informed consent, it

was also recognised that participants had the autonomy to choose not to take part. My ethical stance was based on beneficence, in the form of informed consent, and non-malificence with the intention being to not cause harm (Kent, 2000).

3.6 Development of the postal questionnaire

I considered a postal questionnaire to be an appropriate research method that would lend itself to data collection without the researcher being present. This was to maximise responses from as wide a range of participants across Scotland as possible. Other options considered included structured telephone interviewing, computer assisted interviews and surveys (Gomm, 2008). However, none of these gave the ease of access that I was looking for in this shorter first stage.

A postal questionnaire was an appropriate method of data collection due to the potentially large numbers of respondents across a wide geographical area. It was also economical and relatively easy to develop and distribute. I had to consider that, as there would be no contact between the participant and myself, I may not get the required depth of information. I was aware that there would be no opportunity to check or substantiate any of the answers and remained aware of the low response rate among postal questionnaires, believed to be in the region of forty per cent (May, 2003). I required some classification questions initially to determine the participant's age, gender and caring situation. Thereafter, closed qualitative questions were included, with the option of adding a further response if this was not included in the range of options.

I wanted to give the option for information to be included that may not have been covered by my choice of questions, so I included space for additional comments. This is controversial in research, for example Garcia et al. (2004) suggested that the questionnaire should not finish by asking if there is anything else that the participant would like to add. They referred to this as 'free text comments' (Garcia et al., 2004, p.113) and believed that there were validity issues in their use as there was no guidance for the respondent when they were completing it. The authors maintained that a well-designed questionnaire should not need to look for a response such as this to determine its information, as the questions should be clear. Free text comments may also be lengthy, can lead to problems in analysis or may cover topics chosen by the participant that are not relevant to the researcher. Evans et al. (2005) welcomed free text comments in their postal survey among doctors, believing that it could help in the interpretation of the data and may also influence future questionnaire design. Evans et al. concluded that designing a questionnaire in a structured way using different topics may have enabled participants to give their views in the relevant section, rather than in such a general way at the end. Although realising the potential for subjective opinion to be included in the responses, I decided to combine both suggestions by including free text comments, but also having a clearly identified structure to the questionnaire. At this stage, additional comments may have been relevant to the development of the research question in Stage Two.

The content, structure, format and sequence thus all became relevant to my chosen approach. As I was seeking initial information from this stage of the research, I did not seek to include deviant cases (Lipset, 1963). This would have involved seeking

something untypical within the research. My position of determining individual perspectives meant that I did not need to look for data that did not fit the pattern. Indeed I was not looking for a pattern, only to present carer perspective.

To maximise the response rate I sent out the questionnaires at a time that did not cover a major holiday period. To avoid the school summer holiday in Scotland this meant distributing the questionnaire in early September 2005. Participants were given the option of including contact details, with anonymity assured, in order to receive research findings. A stamped addressed envelope was included to enable swift return to me and to minimise inconvenience for the participants.

3.6.1 Content of the questionnaire

I used Edwards et al.'s (2002) strategies in an attempt to improve the quality and the response rate of the postal questionnaire. This included the participants having confidence in me due to my position in the organisation, use of coloured ink to make the questionnaire easier to read, including a stamped addressed envelope and using first class post. Although the optimum length of a postal questionnaire is said to be six pages (Burns, 2000; Edwards et al., 2002) my questionnaire was nine pages long. I incorporated four separate parts with two or three questions in each part, with large font and tables for ease of reading referred to by Gilham (2002, p.37) as 'visual packaging'.

My existing knowledge of the subject of dementia in people with Down syndrome was essential when deciding which questions to include in the questionnaire. Due to my previous experience of working with, and supporting, people who have Down syndrome and dementia, I was aware of areas of concern, issues and the early signs of dementia which helped to shape the questions. Additionally, a training guide for staff (Kerr and Wilson, 2001) and resource pack for carers and staff (Turk et al., 2001) provided further information on this topic.

The first section of the questionnaire, Part A, focused on the carer's situation by asking classification questions. This included confirmation of whether the carer was a family member or a formal carer, and how long it had been since they had received the diagnosis of dementia for the person they cared for. Part B requested information about the early signs and symptoms of dementia, and identification of the professionals or others that were involved at the point of diagnosis. Part C focused on the carers understanding of dementia. Part D considered the accommodation of the person with Down syndrome and any subsequent or planned accommodation moves.

It was made clear that some, or all, of Part D may not need to be answered if no changes in accommodation had occurred. This explains the longer length of the questionnaire and why for some the maximum number of pages may have been needed, whilst others completed considerably less. This is the reason for including one routing question, despite some resistance to this (Oppenheim, 2004). A routing question directs the person completing the questionnaire to move forward to a later question, without necessarily answering all of the earlier ones. This enabled me to

incorporate questions that covered a range of different circumstances. Routing questions are often used in questionnaires, although have been criticised for their potential to confuse if the participant is directed in a number of possible different ways. I gave clear guidance to the respondent to move forward to a later question depending on their response to a specific question. For example, if the person cared for had not changed accommodation since diagnosis, carers were instructed to move to a later question.

3.6.2 Data collection

I sent information out about the research, on request, to carers on the assumption that the person they cared for had a confirmed diagnosis of dementia. As a result, I had to be aware that some may not have had a correct diagnosis. Dementia may only be suspected due to the difficulty in confirming diagnosis, or even incorrect. I had to assume that those who responded to the original article were satisfied that their family member had a diagnosis of dementia and this was made clear in the initial article.

The questionnaire was piloted with the family and the formal carer who responded first, with their permission. Both agreed to be involved and to give feedback afterwards. I wanted to pilot the questionnaire, in the knowledge that the first attempt can often contain missing data (Addington-Hall et al., 2003). By piloting, and using feedback, this helped to ensure that terms included were in common usage and easily understood. Questions needed to be clear rather than leaving people to work out the

meaning for themselves, albeit possibly incorrectly. This was important as the opportunity would not be there to seek immediate clarification. As a result of the pilot postal questionnaire, I revised the wording to shorten two of the questions and added one further free text question to enable carers to expand on information if they wished. Responses to the pilot questionnaires were included in the overall findings. Holloway (1997) argued that pilot studies might have limitations in terms of contamination if data from the pilot is included in the main results. I took the stance that data collection, and subsequent discussion, would benefit from involving the same people as valuable information could be gained from the pilot, which would improve the subsequent research (Holloway, 1997).

3.6.3 Method of Analysis

Data analysis was carried with the aid of a calculator, and recorded in tabular form, as shown later in this chapter, for ease of reading. Measures of central tendency (Robson, 2009) were determined which gave a mean (average) single figure, for example of the age of the carer and person with Down syndrome. I was able to calculate the mode; the most commonly occurring responses. This gave findings about how often people with Down syndrome were included in decision making, early signs of dementia, who carers first contacted, the number of changes in accommodation and how many were told that they had dementia or given an explanation using different terms. Due to the small scale of the response I was able to enter data directly from the questionnaire to the tables on my computer where I stored the responses. My categories for the tables related directly to the question

topics and the subsequent discussion. I noted any comments in the 'Other' response underneath the relevant table, although these were limited to response to just one question: 'early signs of dementia noted by carers', suggesting that I had covered the main responses in the earlier tick box options.

This process let me determine the signs that carers recognised, or later came to recognise as early indicators of dementia, who they first contacted with their concerns, how far the diagnosis had been shared with the person with Down syndrome and any changes in accommodation that had occurred since diagnosis. In doing so I answered my research question for Stage One.

3.7 Limitations of Stage One

Despite offering a reliable method of data collection due to having standardised answers, the postal questionnaire as a method of data collection has limitations due to the lack of direct contact with participants. The format made it difficult to explore complex issues or opinions and it was not possible to know that the questions had been fully understood by participants.

The objectivity required in a positivist approach prevented me from understanding the individual experience of carers. I did not expect this to be an issue as I was seeking a general overview of carers' opinion and to determine the direction of the second stage of the research. This was to give me an evidence base from which to develop the research due to the lack of existing literature in this area. With hindsight,

had I realised the extent of the lack of awareness of the person with Down syndrome post-diagnosis, and the high number who had not received a diagnosis or explanation, I could have tailored my questions to find out more about this. With the data I gathered, it was not possible to know if the carer had always made decisions for the person with Down syndrome or if the person was even aware of having Down syndrome, let alone dementia. Nor did I use the postal questionnaire to explore the methods of communication already used with the person before and after their diagnosis, which may have alerted me sooner to the need for adapted communication and the importance of knowing the previously preferred method. However, the findings did enable me to develop my approach to Stage Two, by focusing specifically on the experiences of people with Down syndrome.

3.8 Findings

This section will present the findings from thirty-five of forty-five questionnaires received back by the return date of 4th November 2005 (78% response rate). Twenty-three were received from formal carers, and twelve were received from family carers. Findings are presented in this chapter to evidence how data from Stage One influenced the direction of Stage Two of the research.

3.8.1 Part A: Carers and their situation

The average age of those with Down syndrome being cared for was 52.8 years at the time of diagnosis. The average age of men was 51.4 years, and of women 53.9 years.

The average age of family carers was 79.5 for parents and 51.3 for siblings, with the average age of paid carers being 42.5 years. Twenty-five had cared for a person with Down syndrome and dementia for four years or less, ten for more than four years.

Question: What gender are you?

Carer	Male	Female
Paid carer	3	9
Family carer	6	17
Total	9	26

Table 1 Gender of carer.

Twenty-six of the carers who participated were female, nine were family carers, (six mothers and two sisters) and seventeen paid support workers. Nine respondents were male, three family carers, (two fathers and one brother) with six paid carers in supported living projects.

Question: What gender is the person you care for?

Person with Down syndrome	Male	Female
Cared for by paid carer	5	7
Cared for by family carer	9	14
Total	14	21

Table 2 Gender of person cared for.

Fourteen people with Down syndrome and dementia were male, twenty-one were female.

3.8.2 Part B: Early signs of dementia noted by carers

(More than one sign may be noted).

Question: What early signs of dementia were noted?

Early sign	Noted by Family carer n=12	Noted by paid carer n=23	Total n=35	Percentage of group
Change in Behaviour	9	19	28	80%
Change in living skills	7	18	25	71%
Confusion	6	17	23	66%
Change in sleep pattern	4	7	11	31%
Change in communication	5	6	11	31%
Memory loss	3	7	10	29%
Change in understanding environment	2	3	5	14%
Other*	1	3	4	11%
Change in physical health	1	2	3	9%

Table 3 Early signs of dementia noted by carers.

*Other: 1 developed seizures, 1 developed noise sensitivity, 1 talking to dead relatives, 1 fear of going outside.

Question: Who was the first person spoken to by the carer about dementia?

First spoken to	Family carer	Paid carer	Total	Percentage of group
General practitioner	5	12	17	49%
Community Learning Disability Nurse	1	4	5	14%
Family member	2	1	3	9%
Day Care staff	1	2	3	8%
Colleague	0	2	2	6%
Voluntary organisation	2	0	2	6%
Psychiatrist	0	1	1	3%
Social Worker	1	0	1	3%
Psychologist	0	1	1	3%
Occupational therapist	0	0	0	0%
Speech and Language	0	0	0	0%

Therapist				
Person with Down Syndrome	0	0	0	0%
Advocate	0	0	0	0%

Table 4 The first person spoken to by carers.

Whilst perhaps not surprising that the family GP was the first point of contact, the number of times the person with Down syndrome was firstly spoken too is striking, as are the findings below in relation to the potential for awareness and understanding of the changes being experienced.

3.8.3 Part C: Carer perception of the understanding of dementia in the person with Down syndrome

Question: Does the person know they have/had dementia?

Given Diagnosis	Supported by Family carer	Supported by Paid carer	Total	Percentage of group
Yes	1	3	4	11%
No	11	20	31	89%

Table 5 Person with Down syndrome aware that they had dementia.

Question: Does the person know that they have/had memory problems, confusion, forgetfulness or similar?

Told of Changes	Supported by Family carer	Supported by Paid carer	Total	Percentage of group
Yes	4	0	4	11%
No	7	16	23	66%
Already told had dementia	0	4	4	11%
Not answered	0	4	4	11%

Table 6 Person with Down syndrome aware of memory problems.

Four people with Down syndrome were aware that they had memory problems, confusion or similar. Twenty-seven carers had not discussed this at all with the person that they care for. The questionnaire did not probe this further, so the reasons given to the person with Down syndrome to explain the changes that they were experiencing, if any, are not known.

3.8.4 Part D: Accommodation

Question: Where did the person with Down syndrome live when diagnosis was made?

Accommodation when diagnosed	Number of people	Same Accommodation/ provider	Moved elsewhere
With parents	11	8	3
With sibling	3	3	0
Single tenancy supported living	8	7	1
Shared tenancy, supported living	13	10	3
Total	35	28	7

Table 7 Accommodation at time of diagnosis.

Eight people lived in single tenancy supported accommodation, thirteen lived in a group home (intellectual disability), three lived with a sibling and eleven with parents.

Twenty-eight of thirty-five people with Down syndrome had not changed accommodation since their diagnosis of dementia had been made between one and five years earlier. Five of these had between one and five periods of respite for up to

one week. A total of twenty-five carers did not know if a change in accommodation may be a possibility in the future. The following figures show where each move was to, based on the persons accommodation at the time of diagnosis.

Originally lived in single person tenancy:

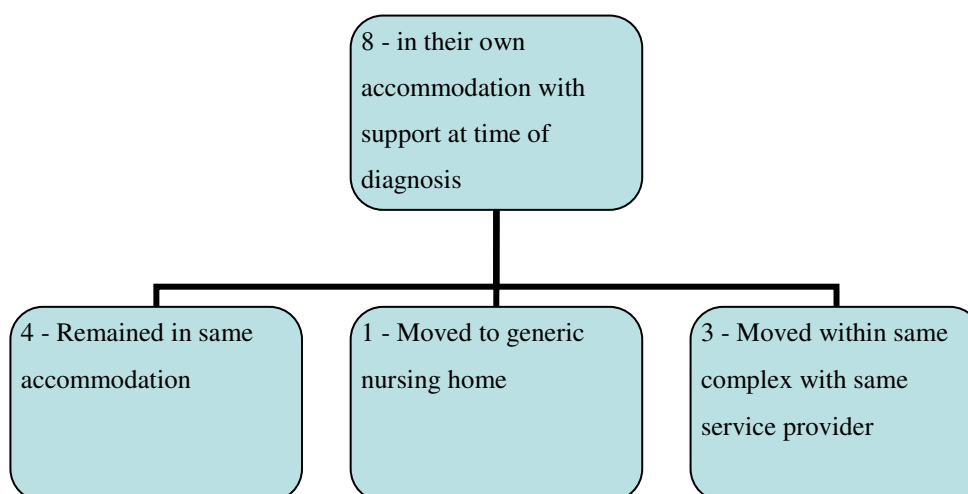


Figure 1 Living in own tenancy at diagnosis.

Eight people with Down syndrome lived in intellectual disability specific supported accommodation in a single tenancy at the time of their diagnosis. Four of these eight had not since moved and did not have any additional supports in place. Three had moved within the same complex, either to another single tenancy physically nearer to staff support or to a single person ground floor apartment. The reasons given were due to higher support needs being identified or to ease problems with mobility. One had a further short-term (three weeks) move to a general hospital ward to be treated for pneumonia.

One of the eight moved to a generic nursing home. Carers identified greater care and nursing needs than they felt able to provide. Two carers noted that it was their intention for the person to remain in the same accommodation for the duration of their illness. Six of the eight carers were unsure if the person would move in the future.

Originally lived in shared tenancy:

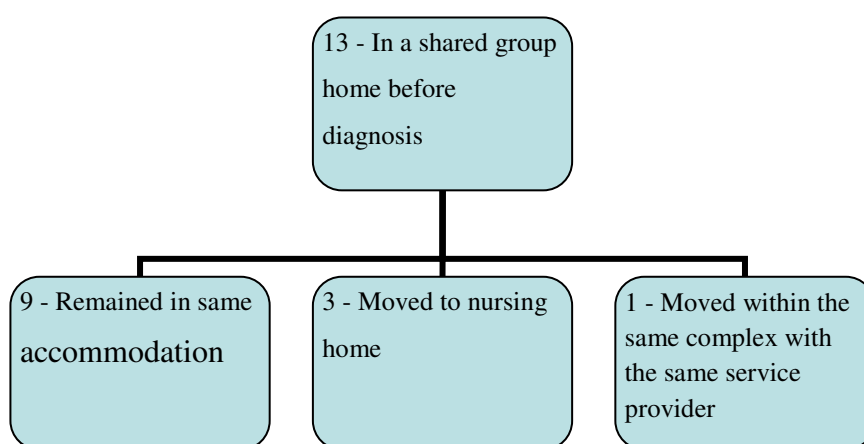


Figure 2 Living in shared group home at diagnosis.

Thirteen of the thirty-five people with Down syndrome lived in intellectual disability specific supported accommodation in a shared group home with between two and four other tenants. Nine had not moved from their original accommodation since the time of their diagnosis. Three had permanent moves: two to a generic nursing home, one to a general hospital for short term treatment and then onto a generic nursing home. One of the ten remained in the same complex but moved to ground floor single-tenancy accommodation.

The reason given in all cases was the disruption that was experienced by other tenants living in the same accommodation, rather than the individual needs or requirements of the person with Down syndrome. Eight carers were unsure if a move would take place in the future.

Three of the thirty-five lived with a sibling, two with a sister and one with a brother. None had moved since their diagnosis of dementia. All of the siblings were unsure if a move would take place in the future.

Originally lived with parents:

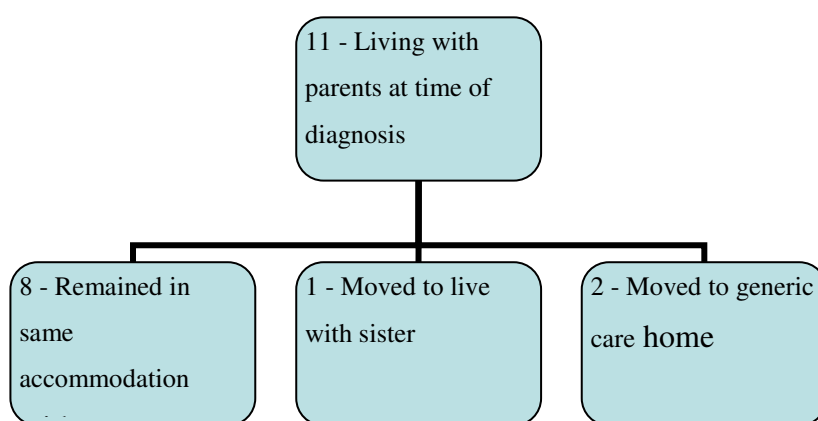


Figure 3 Living in parental home at diagnosis.

Eleven of the thirty-five lived with their parents at the time of their diagnosis. Eight continued to do so although five had short term moves for either respite (four people) or illness (one to a general hospital), and then moved back to the parental home.

Three had moved permanently away from their parents' home, one to live with a sister and two to a generic care home. The reason given for a move to their siblings

was the poor health of their parents. Short-term moves to respite were cited as providing respite for parents and in one case a hospital stay was for pneumonia.

Nine of the eleven carers in this group were unsure if the person they cared for would change accommodation in the future. Throughout the sample, no one had experienced more than one permanent move since their diagnosis.

Question: Who was involved in discussions to change accommodation? (More than one person could be identified)

Who was involved?	Number of times involved (Total number of moves: 11)
Family member	7
Social worker	7
Community nurse	7
Psychiatrist	6
GP	4
Person with Down Syndrome	3
Colleague	0
Advocate	0

Table 8 Those involved in decision to move.

From a total of eleven moves, the person with Down syndrome was included in discussions prior to their move on three occasions. In all cases, the reason for non-inclusion was given as the person's inability to communicate. This can be compared with professional involvement in all moves, with a minimum of three professionals involved in each change in accommodation; family members were involved in nine

moves. Not all of the people with Down syndrome had contact with family members and only one had an advocate.

3.9 Summary of findings

- The average age of those with Down syndrome was 52.8 years at the time of diagnosis. The average age of men was 51.4 years and women 53.9 years.
- The average age of family carers was 79.5 for parents and 51.3 for siblings with the average age of paid carers being 42.5 years.
- Twenty-six of the carers were female, nine were family carers, (six mothers and two sisters) and seventeen paid support workers. Nine were male, three family carers, (two fathers and one brother) and six paid carers in supported living projects.
- Fourteen people being cared for with Down syndrome and dementia were male, twenty-one were female.
- The most common early signs of dementia noted by both family and paid carers were (in order of the number of times mentioned):
 - change in behaviour;
 - change in living skills;
 - confusion;
 - change in sleep pattern;
 - change in communication;
 - memory loss;

- difficulty in understanding their environment.
- Four people with Down syndrome were told that they had dementia; thirty-one were not told anything using the word dementia.
 - Four others were told that they had memory problems, confusion or similar, the remaining twenty-seven were not told anything at all about the changes that they were experiencing.
 - The family GP was the first person consulted when a carer had concerns, the response of the GP is not known, nor where a further referral was made to.
 - Eight people lived in single tenancy supported accommodation when the diagnosis was made, thirteen lived in a group home (intellectual disability), three lived with a sibling and eleven with parents.
 - Twenty-eight of thirty-five people with Down syndrome had not changed accommodation since their diagnosis of dementia had been made between one and five years earlier.
 - Those who changed accommodation moved to a generic nursing or care home for older people.
 - A total of twenty-five carers did not know if a change in accommodation would happen in the future.
 - Three people with Down syndrome were included in discussions about a potential future change in accommodation. This means that the majority of people with Down syndrome being cared for had not been involved in any conversation about their future care or long term planning.

3.10 Discussion

3.10.1 Introduction

There was a high response rate to the questionnaires; twenty-four from thirty formal carers and eleven from fifteen family carers, 78% in each group. Although this is higher than average it may be due to the participants all being members of Alba organisation and being familiar with contacting, and responding to, its staff. Emerging themes are now discussed, linked to published literature.

3.10.2 Gender and age of carers

Twenty-six of the carers who participated were female, nine were male. The average age of parents was seventy-nine. This supports research findings by Fortinsky et al. (2002) that more formal carers in paid posts and family carers are women.

3.10.3 Gender and age of people with Down syndrome

Tyrell et al. (2001) found that the age of people when dementia is diagnosed is 54.7 which is older than the average age found in the postal questionnaire of fifty-three at the time of diagnosis. The questionnaire did not ask the type of dementia.

3.10.4 Early indicators of dementia noted by carers

The lack of significance of memory loss not being the first indicator of dementia in people with Down syndrome echoes findings from elsewhere (Ball et al, 2006; Kittler et al, 2006). A significant issue that this raises is that if the dominant early signs of change in behaviour, confusion and change in living skills are not recognised as early indicators, then diagnosis may not be suspected until much later. Implications of a late diagnosis can include losing the opportunity to prescribe medication that may delay progression, if appropriate, and an increased opportunity for the person to be included in future planning.

3.10.5 First person spoken to by carers

Unsurprisingly, with easy access to primary care services, the most common first contact for carers was the GP of the person with Down syndrome. What the GP does subsequently, and who else becomes involved in future planning, is vital to ensure that social and environmental issues are considered, in addition to physical health. This is especially relevant as environmental and social changes were detected first, rather than changes in physical health. Bond et al. (2002) referred to the medicalisation of dementia, with GPs being viewed as experts who make a diagnosis and recommend treatment, yet do not always refer to community based or non-medical professionals who may be able to offer different supports or interventions. Despite the strong emphasis placed on GPs by carers, there is a lack of training available for them about Down syndrome and dementia (Kerr et al, 2006). In

Scotland, a GP is likely to have no more than five people with an intellectual disability registered at any time on their practice list, making this group a low priority compared with dominant health issues (NHS Scotland, 2004).

9% of carers first contacted staff at the day service used by their family members to discuss specific concerns. In all cases this was an intellectual disability specific environment. Day care facilities for people with dementia in the general population are recorded as valuable and supportive environments (Downs et al, 2002), yet for people with Down syndrome it is often one of the first parts of their daily routine that changes. This is due to perceived difficulties anticipated by staff, inappropriate noisy environments, activities no longer enjoyed by the person or difficulties with travel (Whitehouse et al, 2000). This means that a familiar service is no longer available with the added consequence that older family carers, who previously had this period of respite, are left with additional daytime responsibilities.

3.10.6 Sharing the diagnosis of dementia with the person with Down syndrome.

This was a recurring theme among participants despite research findings suggesting that non-disclosure of diagnosis in the general population without an intellectual disability can have a negative impact on the person and their family (Fearnley et al, 1997). The postal questionnaire showed that 77% of the population were not given any information about the changes that they were experiencing. This would potentially lead to confusion, distress and agitation as has been noted in older people

generally (Bamford et al, 2004). An early diagnosis gives valuable time in the early stages for the person with dementia to make decisions about their future and to allow for carers to access support and information for both themselves and the person that they care for. This is not an option for people with Down syndrome if they are not told either of the diagnosis or of the implications of the changes being experienced.

3.10.7 Accommodation changes

Twenty-eight of thirty-five people with Down syndrome had not changed accommodation, although it is not known if appropriate support, environmental adaptations, specific skills and training for carers were in place. Whilst it appeared that staying at home, the 'ageing in place' option, was the most common this may be due to carers having access to respite care facilities, and having a strong desire for the person to remain where they were. Hatzidimitriadou and Milne (2005) found that parents wanted to continue as the main carers for as long as possible but needed support and information from services to enable them to do so.

Remaining in the same accommodation with additional supports actually occurred in just four cases, with formal and family carers noting that this was only possible if a bedroom was available on the ground floor to allow adaptation, and if staffing levels could be resourced or increased to enable a move within the same intellectual disability specific environment.

Seven people moved elsewhere. This involved a permanent move to a generic nursing or care home, despite research considering this an unsatisfactory option (Zimmerman et al., 2005). Findings support Thompson and Wright's (2001) research that people with an intellectual disability are often moved to care homes for older people at a younger age than specified in the homes' admission criteria.

3.10.8 Future moves

Twenty five carers chose 'don't know' as the option for future accommodation suggesting that although moves are not common in the early stages, there is a high level of uncertainty over longer term planning. It is often in the later stages that crisis moves take place. This suggests that the Edinburgh Principles (Wilkinson and Janicki, 2000) relating to the importance of planning to maximise the opportunity for a person with Down syndrome to stay in their own home are not being met.

Uncertainty over future accommodation is consistent with findings from the Joseph Rowntree Foundation research (Wilkinson et al, 2004) which highlighted the lack of firm plans over future accommodation.

3.10.9 Involvement of the person with Down syndrome

I had to conclude that the lack of a shared diagnosis, or explanation of the changes being experienced, was a contributory factor in the lack of future planning involving of people with Down syndrome. The involvement of professionals and carers, rather than the person with Down syndrome, in any decisions is not a new finding in the

field of intellectual disability (Stalker et al, 1999; Goodley, 1996). Yet, research consistently promotes a person-centred approach, with the wishes of the person with an intellectual disability central to any discussions, for example McConkey and McConachie (2001) recommended that greater consideration be given to preferences over choice of home. Person-centred work has an impact on the general population who have dementia, with an increasing number of people having more of an input to their future care and provision (Kitwood, 1997). The same impact and choice does not appear to be as obvious when people with Down syndrome have dementia, with the potential created for isolation or marginalisation, from both intellectual disability and dementia services, if neither have clear policies and guidance for supporting this group.

3.11 Summary and recommendations

The postal questionnaire was used to gather data about the awareness that carers had of the early signs of dementia in people with Down syndrome and to record action taken post-diagnosis. The use of this method within a positivist methodology enabled me to develop quantitative findings that indicated the early signs of dementia, action taken by carers and the extent of any changes in accommodation. A key finding was the lack of awareness among people with Down syndrome of why changes were happening to them. Most carers said that the person they cared for had not been given any explanation at all of their condition, or the changes experienced, and certainly had not been given a diagnosis.

Findings from this stage were consistent with my earlier literature review. People with Down syndrome were being defined by their situation, their diagnosis and what this meant for carers, rather than having their individual experiences understood. The potential for marginalisation was clear with the lack of the ability of the person with Down syndrome to communicate given as the reason for lack of inclusion in decisions or plans. Even at this relatively early stage in diagnosis, social exclusion was evident in interactions with others and, in terms of wider cultural awareness, through lack of access to a diagnosis of dementia. It reflects the need for the experience of people with Down syndrome and dementia to be sought from their perspective, as part of addressing the lack of existing research literature in this area.

Having this awareness about the lack of inclusion and the uncertainty of carers over the provision and location of future care led me to focus Stage Two on the person with Down syndrome, as explained in the following chapter. The foundations on which to build research that is inclusive of people with Down syndrome and dementia are not currently available in published research, creating an opportunity for me to foreground research methods with this group. As will be explored in the following chapters, my research was ultimately with a small number of people with Down syndrome and dementia over a three-year period of data collection. The longitudinal nature of the research meant that I was able to observe experience as dementia progressed. It also provided a detailed investigation of individual behaviour (Menard, 2002). Data collection ultimately gave me one hundred and one hours of recorded visits, plus copious amounts of field notes and the research experience of

developing methods to include participants from an under-researched group. Chapter Four outlines my methodological process for Stage Two.

CHAPTER FOUR

STAGE TWO - RESEARCH METHODOLOGY

4.1 Introduction

This chapter discusses my chosen methodological approach and considers the rationale for my synthesised approach. As I sought to capture factors impacting on the experience of individuals with Down syndrome and dementia, I drew on phenomenology when collecting, analysing and interpreting my findings. This chapter will expand on this decision, explaining how it enabled me to develop three non-chronological case studies. The literature review and findings presented in Stage One highlighted the need for research that:

- seeks to understand the experiences of people with Down syndrome and dementia;
- maintains a flexible approach as a result of the pre-existing intellectual disability of participants and their progressive cognitive decline associated with dementia;
- incorporates non-verbal communication;
- includes participants with Down syndrome and dementia, whilst respecting the absence of a shared diagnosis of dementia;
- maintains academic rigour.

In this chapter, I firstly rationalise my decision to adopt phenomenology as an approach, with discussion of the opportunities and limitations that this created. Secondly, I introduce my theoretical perspective; social construction, making links between this and the need for adapted communication. Thirdly, I consider my role in the process, and how my chosen approach enabled the inclusion of people with Down syndrome, in the knowledge that each would become increasingly non-verbal. The final part of this chapter explains my methods of data collection and analysis. Throughout, I reinforce the belief that experience is created by social and interpersonal influences (Gergen, 2009) and as such can be co-produced by interactions.

I had originally expected to have a higher number of participants in Stage Two, as will be explained in Chapter Five. When this proved unrealistic I had to compromise, which led me to embrace a longitudinal position with fewer participants. Taking this revised approach gave me different opportunities in relation to the longer period of time I was able to spend with each participant, and the opportunity to develop relationships. I reflect on my own thought process as I grappled with the complexity of changing my research aim from ‘lived’ experience to the impact of observed experience and assessing factors that enabled me to understand this from the perspective of participants with Down syndrome and dementia. Firstly, I give an overview of phenomenology with rationale for this approach.

4.2 Overview of phenomenology

Phenomenology identifies specific phenomena by looking at how it is perceived by participants in a given situation. This involves gathering information through indicative, qualitative research methods and presenting it through the perspective of the participant. Phenomenology emerged from the work of European philosopher Husserl (1999) in the early 1900s. Since then it has seen a number of transformations with the development of different schools of thought. Descriptions have ranged from a substantive philosophy following Husserl, Heidegger and Merleau-Ponty to a distinctive approach encompassing a range of disciplines (Embree, 2010). Confusion over meaning has no doubt stemmed from the widely different interpretation of its scholars. This ranges from an ‘overarching principle’ (Maykut and Morehouse, 1994, pg. 3) that includes quantitative research, to the view of Merriam and Simpson (2000) that situates it firmly in quantitative research. Phenomenology in different guises has been embedded in a range of disciplines, for example education, feminism, anthropology and health, leading to Willis’s (2002) statement that the movement had mutated to meet the differing needs of groups in all aspects of society.

It is Husserl’s (1999) approach that I turn to as my starting point, with phenomenology stating that a scientific explanation has to be grounded in the meaning of those being studied. This means that both the participant and researcher are central to the research process from the beginning through to analysis. Husserl’s belief was that access to the material world was through the consciousness. As a result, all knowledge comes from experience, with the notion of experience

encompassing anything from a physical object to an emotional state. Husserl developed his approach to phenomenology as a means of understanding this consciousness and dealing directly with reality. He took a descriptive approach where individuals are the means through which the structure, or essence, of phenomena may be understood. A phenomenon refers to an event or incident that is considered worthy of enquiry or investigation, especially if they offer unusual or distinctive information (Markey, 1925).

Empirical phenomenology is distinct from the three other variations: individual, hermeneutic and dialogical. Although no account is absolutely fixed, hermeneutic phenomenology generally focuses more on accounts of the phenomenon obtained from literature or poetry (Lavery, 2003). It has different methods of data collection with less emphasis on clarity of method and analysis. Dialogical phenomenology involves the participant in the analysis and decoding themes in more of a counselling approach (Stawarska, 2009), whereas individual phenomenology involves an understanding of the researcher's experience to a greater extent than that of the participant (Bradfield, 2007). This section will continue by presenting the underpinnings of phenomenology, firstly using a philosophical stance, followed by my development of an individualised methodological approach.

4.3 Philosophical underpinnings of phenomenology

For clarity of explanation, and to relay my thought process, I will first present the philosophical underpinnings of phenomenology, before going on to identifying the

methodological issues and questions that I was left with in my research. I then explain how this process led me to develop my own approach. The phenomenological method is said to embrace four key characteristics: description, essence, intentionality and reduction (Husserl, 1999) as a means of understanding phenomena. Each is presented to give an overview before considering their relevance to my work.

Description refers to the aim of phenomenology to describe experience rather than offer explanations (Husserl, 1971). This places the person's experience at the centre. Essence is the inherent meaning that makes a phenomenon what it is. The search for essence comes from intuition and reflection. It involves consideration of what is essential and necessary and what has happened by accident or coincidence. Essence exists whether it is uncovered or not. Crotty (1998) notes that phenomenology must be informed by either constructionism or objectivism. Constructionists assume that the researcher creates a sense of what is real by interacting with real life data. Objectivists maintain that there are actual objects of knowledge, which exist independently, whether or not the researcher discovers or interacts with them, thus objectivity and subjectivity are incorporated, a stance that fits with my approach. Husserl's (1999) focus was also on individual experience rather than how other people experienced the same phenomenon. This has led to criticism of whether a range of individual experiences can be described as an 'essence' (Paley, 1997). A counter argument to this from Griffin (1983) is that some aspects of individuality may be hidden by familiarity in groups with others; therefore it is necessary to explore experience individually rather than collectively.

Intentionality refers to the view that individuals are always conscious of something (Chamberlain, 1974). It is a process whereby the mind consciously focuses thoughts on a particular object or phenomenon encompassing the total meaning of an object, person or idea. Husserl (1999) wrote of noesis and noema in relation to intentionality. Noema is an objective statement of experience, whilst noesis is a subjective reflection (Sanders 1982). The task of phenomenology is to distinguish between common sense beliefs or assumptions and conscious ideas of objects (Holloway and Wheeler, 2002).

Reduction is the process of making this distinction. It is a means of suspending or 'bracketing' any taken for granted assumptions (van Manen, 1982). It is similar to the mathematical process of bracketing that sees a natural attitude put in brackets to place it temporarily out of the question. By doing so any presuppositions are temporarily suspended so that theoretical prejudice does not influence the description of experience. Patton (2002) refers to this as having a fresh viewpoint so that only the experience is seen. Hein and Austin (2001) note that this is followed by extraction of key themes to seek commonality across participants, referred to as imaginative variation. Although Heideggarian phenomenology (Dreyfus, 1991) would allow for brackets to be removed, I decided that its focus on how people made sense of what was happening to them was too far removed from my intention to observe everyday experience. This was particularly important as participants were not aware of their diagnosis. Had I followed my original plan, of conducting research with people about their experience of dementia, this would have been a more

relevant approach. As a result, I followed Husserl's philosophy with the exception of bracketing as will be explained further.

Taking these broad descriptions, I now expand further on the rationale for this approach. In the process of my literature review I regularly came across research articles which claimed to be phenomenological if their primary aim was to research lived experience, indeed I described my own work in this way at the outset. The challenge to using a phenomenological approach, when communication would not always be verbal, is clear in my work. I was aware of the need to look for reasons behind what I observed, in order to contribute to the lack of knowledge base in this area. Although some aspects of phenomenology fitted my research criteria: description, essence and intentionality; reduction appeared less applicable. For example, I intended to place individual experience as central and to understand essence, or phenomena. Phenomenology requires the researcher to bracket their own suppositions before beginning the description of observed experience. Yet, I knew that each individual was not always conscious, or aware, of the full reality of their situation which led me to consider whether I should bracket, or set aside, their intellectual disability or their dementia; I wanted to study individual experience to develop case studies, but I also wanted to compare these experiences and look for emerging themes.

Bracketing is contentious; it is very difficult for a researcher to say that they have put aside assumptions or prejudice. In my research I would also need to bracket any existing knowledge of intellectual disability and dementia; that is put it to one side,

in order to remain neutral with respect of beliefs about a phenomenon. I knew that this would not be possible as without my existing knowledge of both areas of work, it would not have been able to plan or conduct this research, including the content of the postal questionnaire in Stage One. Specifically, I required pre-existing knowledge of both Down syndrome and of dementia, and of the importance of adapting communication as dementia progressed. Consequently, I adopted a reflexive approach by incorporating my own subjectivity and experience (Finlay, 2009). Although I struggled with how far the research could be phenomenological when I held this existing knowledge, I was reassured by Giorgi's (1983) work that neutrality at the point of analysis may be more important than when gathering data.

Just as I recognised the importance of bringing my own knowledge, I was equally aware that the participants would be bringing their own suppositions which I wanted to recognise; they would have their own ideas about the direction and content of discussion. There was potential for my visits to become associated with their social value rather than for research purposes. As I was not seeking the absolute truth in responses, I factored into the process that participants were unlikely to recall accurately due to the effects of dementia. Nor was I seeking the opinions or interpretations of others, such as staff or family, although I came to recognise the importance of the interactions I observed for each participant. In this way, findings were the truth at that point in time according to each participant and this was how I constructed my knowledge. It allowed for reflexivity, acknowledging the impact that I had on the research and enabling me to give the lead to the participants in terms of the direction of my visits. I was further reassured by literature that unintended

consequences formed a key part of the phenomenological approach. This would accommodate any observations or interactions that the participant may not recognise as relevant or interesting, but that offered much in terms of my understanding of their experience. The importance of researcher reflexivity and my intention to study people in their own environments led me to initially consider ethnography as an approach. I remained aware of the need for flexibility as the research progressed in order to maintain the inclusion of all participants. As a result, I looked to ethnography and narrative research for elements that may be incorporated. In an under-researched area this offered me a flexible approach as I was initially unsure how successful my attempts at interaction and communication would be.

4.4 Ethnography

Ethnographic work, a description of people or cultures, uses observation as a key method of data collection with findings often presented as a case study (Gomm, 2008). I initially considered that my main focus may be an ethnographic approach as I expected to be observing people in their own environments. However, I intended to collect data from the participant only, rather than incorporating data from their role in a group or social setting as is often seen in ethnographic research (Hammersley and Atkinson, 1993). Different forms of ethnography are described in research (Gold, 1969). To have used the complete participant approach, and become immersed in the environment of the participants, would have meant that there was no awareness of my role as a researcher. I did not consider this to be appropriate; my role was clearly negotiated in advance and my contact was only with the person with

Down syndrome rather than with a service provider to gain access to the wider staff group within the care setting. More relevant was Gold's definition of the observer, as I made my presence known to the individuals and their carers in advance.

Ultimately the key difference between my work and traditional ethnography is that I did not try to discover what people did, or their reasons, as I observed their actions. An area identified as problematic in ethnography is the lack of control of the researcher over the field setting (LeCompte and Schensul, 1999). This was not an issue in my research as I expected, and embraced, differences between participants and changes over the research period as dementia progressed. As a result, although elements of my research met ethnographic research criteria, such as the reflexivity required, emphasis on observation and learning about experience in everyday contexts, this approach was not my primary focus.

4.5 Adapting narrative research methods

Narrative research is a two-way process through interviews of conversation (Holstein and Gubrium, 1995). This does not necessarily offer 'experience'; rather it may be that narratives tell of activities (Silverman, 1993). However, due to the anticipated non-verbal nature of a large part of the research, I wanted to maintain flexibility with my communication methods. Adopting some techniques from narrative research gave me the flexibility to do so. This was in keeping with a phenomenological approach where non-verbal communication is evident, such as Gilbert's (2004) research incorporating visual methods with people who have profound intellectual

disabilities. I introduced a range of pictures with one of the participants, as will be shown later in Chapter Five. These were used for 'elicitation'; a springboard for discussion (Bryman, 2008, p.19). After trying different directions to determine which style of pictures was preferred, I was able to base communication on this as the participant became increasingly non-verbal. This does not follow the same format as Pink's (2004) work using photographs in research; she advocated that participants were involved in deciding which photographs should be taken. It does, however, follow a similar process as the participant determined which, if any, of the pictures were ultimately used.

In phenomenology, the description comes from the subjects; it is their experience under investigation. Giorgi (1983) criticises this as he maintained that phenomenology, strictly interpreted, depends more on the self and the self-evidence that is shared. This concerned me initially as I was aware of the likelihood of participants being, or becoming, non-verbal. However, I was reassured by van Manen's (1982, pg. 294) interpretation of 'the art of being sensitive' as part of the phenomenological method. His stance was that a researcher should listen to the subtle undertones of a conversation, which he referred to as a literal silence, when no one speaks at all. Although not conducting research with people who had dementia, or an intellectual disability, he believed that it was more important to remain silent rather than intentionally try to fill a silence for the sake of saying something. Hugo (2006) recommended that 'plain statements' were listened to even if at first they appeared to have little relevance to the phenomena under investigation. I felt that it would be appropriate to take this approach as it enabled me to avoid asking repeated

questions if I did not get a response. The majority of existing phenomenological research has been conducted with participants who were able to contribute verbally to the process. My intention was to highlight that non-verbal 'conversations' can be valid research material and although I was reassured by both Hugo and van Manen's approaches, the reality of not filling silences proved uncomfortable initially, as will be explored later.

I needed to build listening time into the research so that this rhetoric of silence could also be included (Wolvin and Purdy, 2010). Bond (1992) favoured filling gaps in stories, even fictionalising what was said, rather than work with fragmented narratives. Instead, I took an approach adopted by Roets and Goedgeluck, (2007) who rejected this notion of fictionalising. They preferred to work with only the information given, even if this proved to be lacking in some detail. I placed less emphasis on chronological sequencing in terms of past activities and memories that is often seen in the development of case studies. This was not identified or recognised as important by the participants, as their current sense of reality was more important. When someone has dementia their current sense of reality is unlikely to be the same as ours; this had to be acknowledged in terms of any stories that were told. As a result, I was able to incorporate elements of narrative research whilst still adapting my approach to each individual, thus taking account of verbal capacity and motivation on the day. Booth and Booth (1994) encouraged this use of a self-developing process when carrying out research with people with an intellectual disability, although it is not an approach that has been recorded in literature with people who also have dementia.

Williams and Keady's (2006, p.166) approach to narratives was that the researcher needed to 'tune in' to what was being said. I intended to tune in by taking time at the start of the research period to get to know each individual. This would take into account what each person was able to say and how they said it, with observations of how they reacted and interacted with their environment. This supports work by Biggs et al. (2000) as it promoted narrative research as a means of creating a sense of well-being in the participant and may have contributed to their willingness to meet me. After determining that a verbal, structured interview was not a viable option for people with dementia, Bamberg (2004, p.368) offered an alternative approach. He maintained that for stories to be identified they need to be 'situated in chat', thus supporting Mishler's (1986) recommendation for unstructured interviews. Cortazzi and Jin (2006) also favoured a conversational style of interviewing rather than formal questioning; this was the style that I adopted in keeping with a phenomenological approach.

My intention was to observe, and spend time with, individuals who had Down syndrome and dementia. Our time together was based on what each person wanted to discuss or do; how they chose to construct their situation, rather than being constrained by narrowly defined categories or questions. This was in order to determine how their individual experiences were constructed in relation to what was happening locally for each person. This socially constructed stance is not new in research with people who have an intellectual disability (Dudley-Marling, 2004) and will now be explored further.

4.6 Social construction

Social construction theory is built on the concept that everyday experiences are learned from implicit social relations rather than explicit or objective reality (Berger and Luckmann, 1967). Although not a unified school of thought, social construction explores these realities. The approach seeks to examine how meanings are formed and how this reflects on the individual in terms of understanding their world (Harding and Palfrey, 1997).

To say that something is socially constructed is to suggest a form of dependency on an aspect of our social selves. For example, something would not exist if we had not built it in that particular form; we may have not built it at all or may have done so in a different way. Assumptions within approaches taken by writers such as Guba (1990) and Jost et al. (2010) maintain that individuals seek an understanding of the world they live in and that they develop subjective meanings of their experience. I followed Hacking's (1999) approach that what is constructed does not only have to be material or physical, it can be a belief or an observation. Research taking a social constructionist approach relies as far as possible on the participant's view of the situation under investigation. It allows for creative and interpretive approaches rather than focusing on specific models or approaches. At a micro level Burr (2003) sees social construction as the interaction between people that takes place as part of everyday discourse. This may be viewed differently by a range of observers; it is the interpretation of each that is important. At a macro level, the importance of language, relations and practices are relevant to show how the notion of 'the individual' has

been constructed. I took the stance that I would be making sense of the data based on its essence, stemming from reflexivity. This included an awareness of what I observed in the lives of participants that was intended, and what happened by accident, or as an unintended outcome. As a result, a socially constructed approach was relevant due to my intention of interacting with the participant to uncover this, rather than seeking factually objective knowledge.

The work of Kitwood (1989) and Sabat (2002) was introduced in the earlier literature review as offering social constructionist perspectives of dementia; Kitwood building on the concept of personhood and offering an alternative way of understanding experience of dementia, Sabat looking at how a sense of Self is recognised in people as dementia progresses. In selecting my methodology, I locate myself within both of these assumptions. I consider the social world to be shaped by cultural and social interactions and experiences, constructed by people's actions, and also constructing, or at times constraining, their own lives. My understanding of dementia is as a construction which brings different understandings of, and attitudes towards, those with the condition.

4.6.1 Language as socially constructed

Communication is a recurring theme throughout my research. Burr (2003) identified the importance of language in a socially constructed position. Communication is not required to be verbal; indeed this has not been my interpretation, as I have focused largely on non-verbal communication. What proved important was that I identified

and understood themes at that particular time and place using the most appropriate means to do so. This was referred to by Burr (2003, p.13) as ‘determined by communication in force at that time’. I used this stance to adapt my communication methods to needs identified at that point in time for each person. This proved a key issue in maintaining inclusion and the individuality of the participants throughout the research. I adapted non-verbal communication with the intent of empowering participants; an approach recommended when working with marginalised groups (Balit, 2004).

I was aware initially that the responsibility for successful communication lay with me (Thurman et al., 2005), as I tried to match what I knew about each person with a potential means of communication. I knew that this would take time, therefore the option of a longitudinal study was appealing as it would enable this process to develop naturally (Klotz, 2004). Davis cautioned that reflecting on a person’s world does not necessarily equate to understanding it; instead the researcher must remain open to learning about themselves and it is only through this self-awareness that they can interpret other experiences or cultures. As a non-disabled, married woman with children I could not equate my experiences to those of a single person with Down syndrome. Instead, I remained aware of my own positioning as one who negotiated and continually learned, particularly about communicating, and of my own position in our relationship, as will now be discussed.

4.7 The role of the researcher

The combination required of a researcher to have specific knowledge of Down syndrome and of dementia is unrealistic for many. This may offer an explanation as to why there is little published work in this field. I needed to develop ways of overcoming this to develop my methods of data collection. Although specific issues are raised in research when research participants are non-verbal and cannot directly convey their experiences, this does not make such research impossible. Instead, I sought to understand how the researcher can have cognisance of different and preferred methods of communication. Keady et al. (2003) developed strategies that included the researcher developing relationships over a prolonged period of contact with the participants, and recording non-verbal interactions.

Research methods most frequently used with people in the early stages of dementia are individual semi-structured or structured interviews and focus groups (Wilkinson, 2002). Practical interventions include reminiscence work, life story, music, singing, dance and art (Clare et al., 2008). Increasingly research is recognising the validity of incorporating such interventions in research (Moos and Bjorn, 2006). This supports the general consensus that people in the early stages of dementia can contribute to research about their own experiences with some clarity, provided that consideration is given to the methods, with flexibility incorporated (van Baalen et al., 2011). Over time this has become even more focused with Petryk and Hopper (2009) breaking down the questions into open-ended episodic (sporadic and intermittent) and open-ended semantic (relating to the difference between meanings of word and symbols)

questions to find out which specifically was more productive in terms of a response. The semantic questions were found to be more successful in people with dementia. I built up this awareness of previous research with people who had an intellectual disability and people who had dementia in order to identify my own strategies for inclusion of a group who had both Down syndrome and dementia. Using this awareness and my existing knowledge of both areas of work, gave me confidence in including people in research who would become increasingly non-verbal.

It is not often acknowledged that researchers need knowledge and skill to understand the nuances that people with dementia may use. Killick's (2004, p.97) example is of the person who used metaphors unintentionally, 'it takes the wrinkles out of your bones', when referring to the benefit of exercise. Consequently, this relied on me adding my own interpretation to what was said to a greater extent than may have been required if the participant did not have dementia, or a progressive condition which would affect communication.

This difficulty with communication is often cited as a reason for the lack of inclusion of people with an intellectual disability in research, as identified in the literature review and in Stage One of my study. Sigelman et al. (1981) felt that participants would be unable to compare themselves with others in a similar situation due to their limited life experience, whilst Cambridge and Forrester-Jones (2001) found that people were unfamiliar with expressing their opinion. Nota et al. (2006) suggested proxy respondents as a way of overcoming this. However, research literature has also shown that there may be an under-estimation of the perceived status of a person with

an intellectual disability, and a lack of awareness of their personal experience and preferences (Jenkinson et al., 1992).

Brown et al. (2010) highlighted that participants in their research did not attach labels to themselves such as 'old' or 'Down syndrome'. Instead they referred to themselves as 'male' or 'beautiful' suggesting a clear sense of identity in terms of their gender and social roles. This is a different identity to that given by formal carers who focus on physical ability or a medical condition, although this may differ depending on how long the carer has known the individual. It reflects the notion that there is more to the lack of inclusion in research than poorly developed research methods. Attitude and low expectations are key factors, including the belief that people with profound disabilities have little to offer in research terms (Klotz, 2004). Based on this my role involved observation of how each person viewed themselves, rather than looking at what they said in relation to what I knew about dementia or Down syndrome. This involved a 'see the person' approach and taking their lead about what they wanted to do or discuss, or just to sit quietly if that was their preference.

This supports Goodley (1996) who maintained that the question of whether a participant is telling the truth or not is not as important as why they are telling their story in that particular way, thus reflecting a phenomenological stance with its emphasis on description, and the social constructionist principle of gaining understanding from the snapshot of experience observed at that point in time for each individual. I intentionally did not seek to fill gaps with carer perspectives, as this

would change the focus of the research and shift the emphasis from the experience of person with Down syndrome and dementia. Stalker et al. (1999) were also wary of filling gaps but acknowledged the importance of checking the information that was given by carers, although with an awareness that it may not be possible to validate all data. Despite not filling gaps with information from carers, I observed a small number of naturally occurring interactions with staff that I included in my field notes. This was as a result of the interaction being part of the participants experience and was therefore key to my understanding.

Highlighting the barriers created by communicating difficulties and planning a strategy for overcoming this was not enough, as the issue still remained of how I could develop research strategies and methods that also enabled communication with participants as dementia progresses, rather than only in the early stages (Zarit and Femia, 2008).

4.8 Adapting communication to support inclusion in research

This section considers the evidence base for adapting methods of communication in research including the rationale for my chosen approach. Exclusion from the research process can perpetuate the sense of ‘Othering’ (Fine, 1994) by reinforcing a particular group as different, or in need of too much additional support. This lack of understanding of communication issues in research is not new. Lubinski (1995, p.66) focused on a ‘learned helplessness’ where a point is reached that further action is considered impossible as the person is believed to be unable to communicate. When

this happens in practice, others stop expecting or seeking a response or feedback and instead see only the difference; a key factor identified earlier in increasing marginalisation. Lubinski argues that this does not mean that the person lacks responsiveness just because they have a delay in responding. Goffman (1990) wrote of a 'spoiled identity' if someone is labelled in a negative way. This was important to me as I already knew from Stage One that low expectations had been placed on those cared for with Down syndrome. Goldsmith (1998) agreed that the more we expect from a person with dementia, the more we will get. I saw this as something that I could apply in a research context, where seemingly small choices such as where to sit and when to meet can empower the individual. This confirmed to me that my time with participants would be led by them rather than me.

Although signs and symbols are a recognised form of communication, not everyone with an intellectual disability, nor all researchers, will have learned to use alternatives to verbal methods of communication. Thurman et al. (2005) maintained that it was the responsibility of the researcher to identify, learn and try to replicate individual signals and cues. Without doing so, the research may not continue and knowledge in that particular area may not be furthered. Research acknowledges the need to take time when communicating with people who have dementia and that it should be a mutual activity (Goldsmith, 1998; Killick and Allan, 2001). Most examples of how to do this effectively include body language and eye contact. However, correct interpretation of facial expressions may be missing, leading to a lack of awareness among others of the emotion being experienced. Encouragement is given to look for 'windows of expression' (Killick and Allan, 2001, p.45) which

often relies on the skill and awareness of the researcher. A person with dementia may take longer to speak although this does not mean that they are unable to do so. I knew that I would need to be aware of the pace of the conversation and remain aware that a response may come much later although may still be a meaningful part of a conversation or interaction. For example, verbal interaction has been recorded in care homes as lasting just a few seconds in many cases, with conversation being one sided and not perceived as having depth or meaning. Yet, observers were able to note appropriate responses that came much later in the interaction and were missed by staff (MacDonald, 2005). Communication difficulties highlighted in research include difficulty in word finding, repetition, frequent changes of subject, and reduced understanding (Whitehouse, 1999).

Direct questioning is not the most appropriate form of communication in research with people who have dementia. Innes and Capstick (2001) suggested that if a person does not have the answer, this may undermine their sense of Self. Killick (2004) maintained that asking a person with dementia to repeat what they had said may not be effective, as they might not hear the question due to focusing on what they were about to say next. In such cases it would be insensitive to ask a person to repeat their statement. This proved to be the reality in my research, as one participant in particular became increasingly non-verbal and difficult to understand. Keeping Killick's research in mind enabled me to not keep asking him to repeat but instead to record in my transcription that the comment was 'unintelligible'.

Research suggests that staff believe people with dementia pick up on the mood of their carers and responded similarly (Ward et al., 2008). Ward et al. gave the example of a resident speaking the same two words every day, but it was how she said them that indicated her emotional state. Most participants in this research did not use verbal communication but were shown to increase their movement to certain music and familiar visitors. This was noticed by the researchers but not by staff, who were not supported to develop their communication skills when there appeared to be an assumption that the person could not communicate verbally. Dementia was seen as an end to communication rather than the opportunity to embrace new and potentially innovative ways of interacting. I remained open to the possibility of using music as part of my interaction with participants, something that again proved relevant with one participant who was able to sing for longer than she was able to speak.

Communication difficulties recorded with people with dementia typically focus on the use of language, with an associated increase in isolation as skills decreased. A further area of difficulty is that automatic responses can occur even when the condition is advanced, such as 'I'm fine' when asked how a person is. Innes and Capstick (2001) recorded that this form of social speech may be maintained for longer, such as greetings or generalities in conversation. I was unaware at the start of Stage Two if the participants were able to communicate verbally or not, although my priority was to ensure that their involvement was maintained as communication changed. I also needed to remain open to some, or all, maintaining a level of verbal communication, as dementia progressed. This can lead to an assumption that the

person is more cognitively aware than they actually are (Sabat, 2002) and was something that I remained aware of.

Touch as a means of communication has been included in research with people who have dementia (Snyder et al., 1995). I was also prepared for this to be important to the participants. This has been found to be successful in research if it was appropriate to the individual and something that they had previously enjoyed. Killick and Allan (2001) wrote of researchers mirroring the actions of the person with dementia as part of the process of interviewing, including copying movement and gestures. It also meant not speaking if the person does not speak, which was acknowledged as difficult for researchers new to this approach. I understood that body language and visual cues would be important especially if there was no verbal communication. I knew that I had to do more than listen as my interpretation of non-verbal communication would be equally, if not more, important.

An example of this was given by Ward et al. (2008) who showed that residents with dementia in care homes spent most of their time in communal areas with staff. Communication with staff followed the clearly defined process of a beginning, sign of intent, confirmation of task completion and closing remark. Not all of these stages were verbal, with some including touch. If the resident was thought to be aware of what was happening next, then there was usually less verbal interaction. In some instances, speech only took place if a resident did not comply as the staff member expected. Even then this was a narrative on the part of the carer, rather than a conversation, described by Ward et al. (2008, p.638) as 'care speak' and was usually

rhetorical. The researchers concluded that without communication there were sustained periods of no contact, leading to a lack of attachment in the care relationship. This increases the segregation and sense of isolation felt by the person with dementia.

The combination of an intellectual disability plus a cognitive condition with a rapid progression, leading to increased and changing care needs has been a step too far, in terms of communication, for most researchers. This section has evidenced some of the reasons for this and has rationalised my decisions in my role as a researcher to:

- allow periods of silence;
- accept the potential for therapeutic interventions to be introduced into methods of communication, such as music;
- avoid closed or direct questions;
- recognise that metaphors or alternative words may be used, due to difficulty in word finding;
- maintain the expectation that participants would be able to take part in the research and that it was my role to facilitate this as dementia increased;
- not fill in gaps, or seek additional information, from staff;
- be prepared to use non-verbal methods of communication and of the potential importance of touch;
- not ask for a response to be repeated if this may cause distress or annoyance;
- look for expressions of emotion, even if non-verbal.

I continue this chapter by discussing my selected methods of data collection and analysis with rationale for each, and for approaches that were adapted or excluded. This approach enabled me to include non-verbal participants as case study participants, even though not all of the typical case study data collection methods were appropriate. Rather than interviews, commonly used in case study research, I have included informal conversation, pictorial documentation and field notes along with the more traditional method of observation as will be discussed.

4.9 Methods of data collection

4.9.1 Observation

Observation proved invaluable in developing the case studies, as I witnessed this in ‘naturally occurring situations’ typical of a phenomenological approach (Denzin and Lincoln, 2011, p.83). The research in Stage Two took place in the home environment of the three participants where I was able to build up patterns of behaviour or explanations, based on my observations. This was preferred to an approach that tested a hypothesis (May, 2003), although I also expected to collect objective data, for example related to the physical environment. I remained aware that observation would be recorded and interpreted from my perspective, which is accepted in phenomenology, although with an emphasis on turning or redirecting these observations into areas of the research worthy of further investigation (Vallack, 2010). The first turn within my research came after realising that the participants were not aware of their diagnosis. A further turn was after noting aspects of care that

were neglectful and required a more practical input into my visits, particularly at mealtimes, as will be reflected on further in Chapter Seven.

4.9.2 Field notes

A traditional approach to observation and fieldwork, originating from anthropology (Hendry, 2008), includes copious field notes. I selected field notes as preferable to video recording, although later came to recognise how valuable the use of video may have been. My rationale was based on a desire not to appear intrusive to participants combined with concern over the technical requirements of operating a video camera at the same time as conducting research (Vollandes et al., 2007). My early reading suggested that participants who were aware of obtrusive researchers and recording devices ‘may well talk more, or talk less, or just talk differently’ (Edward and Westgate, 1987). Instead, I selected the less intrusive digital voice recorder, something that I was already familiar with. However, I later considered that as the participants became increasingly non-verbal this would have accurately captured, and ensured a permanent record of, our interaction. I also became aware of successful research using video with people who had dementia (Cook, 2003). Additionally, the overtness of the video camera may have served to remind the participants of the nature of my visit for research rather than social purposes; the counter-argument being that we may not have developed a relationship to the extent that we did. My observation and field notes were transcribed and analysed, as is discussed later in this chapter, to develop three case studies.

4.9.3 Case study

The term case study refers to a specific form of social enquiry that is distinct from other forms, such as surveys or interviews. Usually the latter collects a range of information that can be limited in depth, whereas the case study can be focused on an individual or an event in more detail (Gomm et al. 2000). This may be an organisation, a family, a community or an individual. My selected methods of research lent themselves to incorporating case studies, something made possible by having a small number of participants and a long period of time to conduct the research. The cases in a case study are often selected on the basis of their suitability (Denscombe, 2003) because they represent the wider group with findings that can be generalised. Cases may also be selected on a pragmatic, or practical, basis, due to time or resource restrictions with the sample chosen for convenience reasons for example, ease of access or geographical location. Chapter Four will discuss how my research in Stage Two was developed pragmatically, due to time restrictions and also on the basis of the participants being part of the wider group in question. It will also explain why, although representative as part of the wider group, the small number of participants meant that those involved were not representative of all accommodation or care settings.

4.10 *Methods of analysis*

Using Yin's (2009) approach I incorporated two layers to my analysis, firstly thematic analysis of the transcribed data. Identifying themes from the data

determined the content for each individual case study as presented in Chapter Six. Secondly, I used cross case comparison (Yin, 2009) by identifying commonality in factors that impacted on the experience of the three participants. This was developed thematically from the three individual case studies. The rationale for both layers of analysis will now be considered in more detail, with the actual process explained, and examples given, in Chapter Five.

4.10.1 Analysing case studies

My approach was consistent with that of Cohen (1987). He described the process of analysis in phenomenology as being immersion in the data by reading the transcripts several times, identifying common themes and describing the experience of the participant through individual structural social descriptions, or case studies.

Although the most common data source is the verbatim transcript, I remained aware of the importance of not overlooking non-verbal observations such as body language and gaps in the conversation, including extended periods of silence (Giorgi, 1983).

Common features in phenomenological analysis are dividing data into units, transforming these units into meaning and tying together the meaning as a general description of experience (Polkinghorne, 1995). As I had over one hundred hours of transcribed data, plus field notes, I needed to keep this manageable. My analytic strategy was to develop a 'case description' (Yin, 2009), recommended when faced with large amounts of data.

To identify individual topics and themes from the transcribed notes I developed a table for each participant, as part of building up the content of the case studies. I was looking for individual experiences at this stage, rather than commonality. As is reflected in the case studies in Chapter Six, this led to some differences in emerging themes, for example mealtimes were an issue for Hannah and (later in the research process) for Andrew, but less so for Lucy. The example below shows an extract from the table I used to build up content for each case study, based on emerging issues from the transcribed data for each individual. Three themes are shown here as an example; this was added to, and developed, for each participant. An extract from a completed table is shown in Chapter Five.

Andrew	Presenting issue or incident
Theme	
Communication	
Observed interaction with environment	
Observation of expression or emotion	

Table 9 Developing case studies.

I followed Yin's four key criteria for analysis when developing the individual case studies.

- I initially transcribed all of the evidence: I began with all of my transcribed data and field notes, rather than only transcribing data that I believed may be relevant.

- Although starting with all of the data, I included only the most significant aspects as I developed each case study. This was by looking for emerging criteria that conveyed individual experience.
- I addressed rival interpretations: as I developed each case study I was able to refer back to the literature to determine if my interpretation had been viewed differently by another researcher in similar circumstances. Although the lack of existing literature reduced the number of potential other interpretations, this is incorporated into my discussion in Chapter Seven. For example, I noted that my understanding of Lucy's decision to stop attending her day centre was consistent with research findings elsewhere, rather than research offering a rival or different interpretation.
- I used my prior expert knowledge: awareness of the subject matter is recommended in case study analysis, and reinforced my decision to include this as part of my methodological approach.

In taking this approach, I rejected aspects of phenomenological analysis recommended by other authors such as Priest (2002), who returned her accounts back to the participants for checking, amendment and feedback. This was not possible due to each not knowing that they had dementia; it would be inappropriate for the participants to read this information. I was also aware that not everyone who participated may be able to read, which proved to be the reality. Although I could have read out my notes, as short-term memory is affected by dementia I did not consider this to be acting in the best interests of the participants as they would be

unlikely to remember. I acknowledge that, in different circumstances, this may have increased validity and reduced any potential for inaccurate reporting.

4.10.2 Cross case comparison

The next stage of my analysis was to incorporate Yin's (2009) procedure for comparing case studies to look for commonality. To do so, I again used a table as shown below, with examples of some of the common emerging issues. Further themes were added as I compared cases. Again, a sample of a completed table is shown in Chapter Five.

Whilst themes from the transcribed data led to the development of individual case studies presented in Chapter Six, the emerging themes from cross case comparison enabled me to highlight key conceptual and practice issues that were observed to impact on experience, as will be discussed in Chapter Seven.

Themes	Andrew	Lucy	Hannah
Self 1			
Self 2			
Self 3			
Verbal communication			
Non-verbal communication			

Table 10 Cross case comparison.

This goes beyond the single features of a case study and enabled me to note where the most consistency in experience was observed. Taking single factors from case studies, and only looking at them individually, can unduly simplified the phenomena under investigation, particularly when reducing a large volume of data. By adding this additional layer I sought to add more depth to my findings and highlight areas that impacted on the shared experiences of the participants.

4.10.3 Alternative methods of analysis

In deciding which methods of analysis to incorporate, I also remained aware of alternative methods that I discounted. One such approach was discourse analysis which initially appeared to lend itself to my research, despite my concern over its emphasis on use of language and the spoken word. Discourse analysis sits well with subjective research and is often seen in phenomenology where the essence is a product of social interaction (Cresswell, 2003). Whilst discourse analysis would have guided me to focus on what was left unsaid in addition to the spoken word or gesture, this was not something that I pursued further due to the changing capacity of participants. Nor was I intentionally looking at the interaction of participants with others. Instead, my selected approach to analysis offered me the opportunity to remain focused on individuals, before looking at the cases together in cross case comparison.

Similarly, I initially considered using interpretive phenomenological analysis (IPA) as I used purposeful sampling, a small sample size, and was seeking an interpretative

approach. IPA is a systematic and practical approach to analysing phenomenological data developed by Smith et al. (1997). It has been widely used in determining experiences, often of health or illness in symptom research. I quickly became aware, as I transcribed, that the limited amount of verbal conversation I was recording and observing may restrict the grouping of different layers of themes usually seen in IPA. The crucial link between phenomenological description and interpretation is the accounts of the participants themselves. This is usually derived from semi-structured questionnaires along with commentary on the data, extensive use of quotes and the emphasis placed on the role of the person as an expert in their own condition or situation (Plummer, 1983). Most IPA research rules out non-verbal behaviour and instead uses only that which is recorded and transcribed (Smith and Osborn, 2008). The role of the researcher is often in probing initial answers as part of data collection. Instead, I decided to focus on how people communicated about a phenomenon in a more general way, rather than relying on a level of cognition and understanding that was framed through language and verbal communication.

4.11 Summary

My intention was to understand the experience of participants, despite each person not knowing of their diagnosis or being able to reflect on its impact. In grappling with the methodological approach it has become apparent why the most commonly used research frameworks rely on verbal communication. Recognition of the marginalised status of people with Down syndrome and dementia is reflected in my approach to understanding how participants constructed their everyday experience. I

have adopted a phenomenological approach using verbal and non-verbal methods. Crucial to the development of my approach was how far I could include an already marginalised group, in the knowledge that further change in cognition and communication would be experienced, due to the progressive nature of dementia.

In order to address these issues, I have explained my rationale for taking a phenomenological stance to understand and describe experience, although without the bracketing of my existing knowledge usually seen in Husserl's approach. This is due to its relevance in research with a marginalised group, previously excluded from the research process, and the specific knowledge required of non-verbal communication.

As part of my approach, I have included a strong emphasis on observation and reflexivity, something more often seen in ethnography, and have also incorporated elements of narrative research, but in a way that gives greater prominence to non-verbal methods whilst ensuring that the direction of our 'conversation' was led, and constructed, by each participant. My methods of data collection have been presented to explain why I incorporated observation and field notes and rejected the use of interviews, typically used in case studies. Analysis was in two parts, firstly developing case studies based on themes identified in my transcribed data. This was followed by cross case comparison to highlight areas of commonality and emerging issues from the case studies that gave insight into the factors that impacted on, and affected the experience of, people with Down syndrome and dementia.

In order to overcome the complexity of ensuring that the experience of the person with Down syndrome and dementia is the primary focus, I employed a series of approaches as shown below.

- Recognising the importance of an individualised method of communication to produce individual descriptions of experience.
- Using non-verbal conversation as a means of engaging with participants, rather than a typically verbal narrative.
- Not looking for chronological information.
- Recognising the importance of the person's home environment in contributing to their overall experience.
- Understanding the importance of silence.

Building on a social constructionist approach this meant that I would:

- not make any assumptions about ways of understanding experiences;
- remain open to individual circumstances and accept our interaction as relevant to that time and place for each individual;
- develop a co-construction approach with each participant.

Having explained and rationalised my flexible approach to the methodology I now present the methods of data collection.

CHAPTER FIVE

METHODS FOR CONDUCTING THE RESEARCH

5.1 Introduction

This chapter describes the methods used to collect and analyse data. The synthesised approach that I took suggested an exploratory focus from the start. This proved to be the reality as the methods continued to develop and be adapted throughout the process as dementia became more advanced for each participant. This chapter is presented in two sections. Firstly, a description of ethical issues, access, sample and consent. Secondly, I explain my procedure for collecting the data and my analytical process.

Throughout, I reflect on how far I was able to maintain an approach that enabled each individual's inclusion for the duration of the research period, which for one participant, Lucy, was through to the end of her life. Lucy became increasingly non-verbal and reliant on non-verbal communication within a year. Another participant, Andrew, maintained verbal communication throughout the research period, despite becoming increasingly difficult to understand. The third, Hannah, had limited verbal capacity at the start, just a few words and short sentences, although this was lost within the first year of my visits. I will begin by considering the ethical issues that arose as part of the process.

5.2 Ethical issues

I have previously highlighted the ethical dilemma created by the nondisclosure of diagnosis to the participants. For this reason, the information sheet for participants (Appendix C) and consent form (Appendix D) in Stage Two did not contain the word ‘dementia’. Instead, the title of both was ‘The care experience of people with Down syndrome’.

In retrospect, it may have been more appropriate to use ‘Observation of, and interaction with, people with Down syndrome’ although, at such an early stage, I did not realise that the impact of individualising communication methods would be as significant as it proved to be. Using ‘experience’ made it possible for the same wording to be used on information sheets for people with Down syndrome and for carers, whereas the longer title may have been difficult to understand. An early assumption I made was that each person would have an opinion on their care, support and environment, whereas the focus in reality was more subjective, based on my observations.

The questionnaire in Stage One was developed for carers of people with Down syndrome and dementia, so I was as sure as I could be that my sample group in Stage Two already met the required criteria of having a diagnosis of dementia. I was told by each person’s main carer before beginning Stage Two what their understanding was and what they had been told, if anything, about their condition. In retrospect, had I revisited the larger sample and specifically invited those whom I knew to have been

given an explanation or diagnosis, this may have resulted in a different research project, or a comparative study between the two groups.

The Ethics Committee who authorised the research did not raise the potential for the lack of shared diagnosis as an issue. An application was approved by the Multi Research Ethics Committee (MREC) Scotland A Committee in 2006 after application under the Adults with Incapacity (Scotland) Act 2000. The Committee specified that consent must be given by the person with Down syndrome themselves at the start of the research, but that contact may continue if the participant subsequently became incapacitated. Repeated or regular consent was not requested. With hindsight, I would have questioned this. At that time such a Committee was relatively new in Scotland. The framework from which the Committee was developed was intended to support the role of service users in research. Clegg (2002) acknowledged that an increasingly legalistic culture has led to people wanting more from an ethics committee than it can deliver in reality. However, the Committee were satisfied that although consent was essential, it needed only to be given only at the start of the process. Despite this, for reasons of good practice, I sought ongoing consent throughout the data collection period and I ensured that a session did not continue if the participant appeared too tired. My method of communication for affirming consent varied; at times this was verbal but it also took into account non-verbal body language. I did not rely only on my own judgement if a participant could not consent verbally, as I also asked a staff member to confirm that, in their view, the person was willing for me to visit. I maintained the stance that whilst having a responsibility to behave in an ethical manner and record my observations accurately I

also, professionally and personally, was unable to stand back if I witnessed potentially dangerous or harmful situations arising as will be highlighted in Chapter Six.

5.3 Access

I used the postal questionnaire in Stage One to ask if the person with Down syndrome being cared for would be willing to take part in Stage Two of the research. This was a tick box for the family carers or paid staff to indicate if they would be willing to discuss, with the person they cared for, the possibility of them participating. By doing so, the carer was the gatekeeper for Stage Two. Carer perception of the ability of the person with Down syndrome to take part in research was likely to influence their decision about whether or not to tick the box. Findings from Stage One had already showed that carers were likely to have low expectations. Six carers ticked this box and were contacted prior to Stage Two by letter (Appendix E) to advise what this involved, with an accompanying information sheet and reply slip (Appendix F) and a stamped addressed envelope.

Although consent was sought from the person with Down syndrome, carers were also informed of the process via the same information sheet. This was because I anticipated that carers may need to give additional support should the participant have become distressed at any point, or ask questions before or after my visit, although in reality this did not happen. As a courtesy, I wanted staff to be aware of when my future visits were, especially in the shared residential establishments when

different staff would be working on shift during my visits. At this stage in the process, I expected my interaction to be predominantly with the person with Down syndrome only, and for this reason I did not seek consent from individual carers for Stage Two. I had not anticipated the extent to which my occasional observation of interactions would have an impact on each person's experience, as will be explained in Chapter Six and discussed further in Chapter Seven.

There was no stipulation that the participants should be able to communicate verbally. As this has been shown to be a common reason for non-inclusion, I specifically did not use this as an exclusion criterion. Instead, I was prepared to adopt alternate methods of communication to ensure that inclusion was possible. As an ethical requirement was that the participant was able to give consent to take part at the start of the research process, I asked for a period of two years or less from a diagnosis being given. This was very much an estimate based on literature suggesting that dementia progresses more rapidly in people with Down syndrome (Ball et al., 2006). This made a two-year cut off difficult, but it served as a guide for carers to help determine if the person they cared for may be able to take part. I was trying to ensure that the person was more likely, in the early stages, to have the capacity to consent and more likely to retain capacity for longer during the research period.

5.4 Sample

The response rate using this approach was far lower than in Stage One. Of the six carers who came forward for further information after discussing this with the person

they cared for, four were formal carers and two were family carers. Subsequently, after receiving more details, one of the formal carers informed me that although the person she supported had expressed an interest in taking part, her sister, also her legal guardian, did not wish this to progress as she did not feel it to be in her sister's best interest. Two of the formal carers felt that the person they cared for would not be able to understand the research process.

The three remaining people with Down syndrome, whose carers had discussed this with them, lived in three different accommodation settings. All subsequently agreed to take part, which enabled me to observe participants in different care settings. Although unintentional, this gave representation from three locations of care: an intellectual disability group home, own tenancy with outreach support and a generic care home for older people. The main care setting not included was living with family, either parents or a sibling.

My sample was therefore selected practically based on access through gatekeepers. It was purposive (Silverman, 2004) as the potential sample group contained only people who had Down syndrome and dementia and as my intention was to observe in depth, a small number over a prolonged period of time was sufficient for the depth required. Geographically all three participants were from the same area in Scotland. This was practical due to the time factor in visiting over a long period of time, whilst also working full-time.

I was aware from the start of the possible attrition rate if any of the participants progressed through to the end stages of dementia and death during the research period. This proved a reality as one of the participants died two and a half years into Stage Two. The insight gained through her eyes during her end of life care was invaluable to the research as a whole. As a result, her observed experiences have been included and I also write about her end of life care and funeral.

5.5 Consent

The consent form was developed in the style of a question and answer sheet to enable people to easily understand the information that they were being given. It has been recorded (Kent, 2000) that people will remember more if they read brief questions rather than a large amount of information at one time. To ease understanding pictures were used for consistency on both the consent form and information sheet. I included a photograph of myself at the bottom of both. One participant, Lucy, whom I had not previously met, recognised me when I went to see her and pointed excitedly to the photograph on the consent form that she had received before my arrival.

Consent was sought to publish the findings, with confirmation that names and photographs (of communication boards or similar, if used) would not be included other than for the purpose of this thesis. Photographs were not taken of the participants.

Although my research aimed at including only people with Down syndrome, it would have been detrimental to exclude naturally occurring interactions that I observed during the process of data collection. Such occurrences added to the depth of the data, and it emerged as part of analysis that I was able to understand some impact based on my observations of interactions with others. I ensured that staff and family members in this situation were aware of my presence and of my role, although I did not formally seek consent from them. I remained consistent in my approach throughout this stage of the research by turning off the voice recorder when someone else was present, and instead writing field notes.

After a few weeks, I realised that participants were agreeing to see me very readily and greeting me affectionately. I had to consider that they might be consenting to our meetings for regular companionship rather from a desire to take part in the research. This highlighted the lack of social contact or stimulation that may otherwise have been received. Despite this, the overarching principles of avoidance of harm remained. I tried to balance non-maleficence, or no harm, with beneficence, potential benefits, which may have been social benefits (McLachlan and McHarg, 2005). My intention was to give as much control as possible to the participants as they determined the time of day, day of the week and frequency of my visits.

5.6 Data collection

In this section I will explain the process of data collection using: observation, field notes, recorded conversation and interaction using adapted communication. By

giving the lead role to the participant during our interactions, I was attempting to empower each to direct our conversation and time together. Participants determined whether or not we met, when the session would end, what the topic of conversation was or whether we would sit quietly, hold hands, look at pictures or objects or sing. This is presented further in the following chapter when I present the three individual case studies.

I was reassured from developing my methodological framework that evidence collected in phenomenological research and for case studies did not have to be verbal. I expected to, and did, use pictures, photographs and a kinaesthetic approach (communication, tactile and body language). I agreed with Simons (2009) that comparing a number of cases within the same setting, or organisation, was not always valuable as each would still have different experiences as individuals. Instead, I studied each participant based on their observed experiences, plus I recorded informal conversation and documented field notes. This included detail of the person's physical environment and, on occasions, how the participant responded to staff. I became fully immersed in the process, whether our time together was minutes or an hour. My field notes tell of concern as I left Andrew alone in his flat and anxiety when leaving Hannah. Trying to understand the world of each participant gave me insight into how they perceived themselves, even without being aware of their diagnosis. This is explored later in Chapter Seven as part of emerging data from cross case comparison.

The length of each visit was between five minutes and one hour fifty-five minutes. Using an approach developed from narrative research methods I let each participant discuss, look at pictures or photographs, or sit quietly if they preferred. I did not have a series of questions, instead adopted an informal conversational style. The pictures used to stimulate conversation or engagement with Lucy are shown below with explanations of their use later in this chapter, and further detail included in the case studies in Chapter Six.



Image 1 Pictorial methods of communication

With permission, visits were digitally voice recorded to ensure accuracy and for ease of analysis. When transcribing I noticed the length of silences between speech, and used spoken observations as a way of recording non-verbal communication. This was the point at which, with hindsight, video recording would have also been a relevant method of gathering data, especially to check non-verbal interaction and show the range of emotion. Despite my initial reluctance to introduce this, due to concerns at intruding more obtrusively on the participants or creating a less relaxing environment by having the video camera present, it may have been a valuable tool.

Giving control to each participant had the advantage of being the most natural for each individual; it was relaxed, informal and in their home environment. I used

communication familiar to, and adapted for, each individual adopting Brewster's approach that people respond best in the 'real world in which they live' (2004, p.35). Allowing conversation and not asking structured questions meant that I listened and observed in order to make sense of the series of events presented. With those who communicated verbally, I listened to what they wanted to talk about and joined in with their conversation. These methods of data collection are now considered in more detail.

5.6.1 Observation

This section considers in more detail how I collected data from the three participants. By observing each person individually, and through the use of verbal and non-verbal cues, I was able to see what happened in their daily lives. This, plus observations of naturally occurring interactions with staff and a family member, proved invaluable when understanding factors that impacted on their experience.

Observation enabled me to record instantly what I saw and any interactions that I witnessed. I took copious amounts of notes and voice recordings during this data collection period, leading to lengthy transcripts and notes for analysis. It was important to transcribe soon after my visits to avoid a back log of transcripts. It also meant that I was able to listen again to the recordings to ensure the equipment had worked correctly and also to remind myself of what was spoken or observed. The length of visits varied, even for the same participant there was no consistency in the time we spent together, although I calculated that the total amount of time with all

three participants was 101 hours. Although some were much longer than others this varied, and at times I spent lengthy periods with all three whilst on other occasions a very short amount of time, often recorded in field notes. It has been suggested (Myers, 2000) that although observation shows behaviour (what) it does not give reasons (why). I saw the 'what' as being relevant and I picked up on what the participant said or did.

5.6.2 Field notes

The areas that I observed and recorded during each visit match many of Angrosino's checklists for field notes (2004). Some involved interactions with others and included:

- a description of the physical setting: the room where we met was usually the person's private space, even within a care home;
- a description of behaviour and interactions;
- a record of conversation, or interaction, that took place with participants when the voice recorder was turned off, for example when I was entering or leaving the building.

I carried my notepad with me and kept it on my knee when conversing with participants to ensure that my recordings were not covert. It was important that my notes remained structured and in a consistent format. I recorded events in the sequence that they took place and recorded any silences, or lengthy pauses, that were

not included on the voice recorder. It was only later, when transcribing, that I noticed the significance of this. For example, when a participant answered appropriately after a lengthy gap or returned to an earlier subject that they preferred to talk about.

Field notes recorded a thick description of what I saw and heard at the time (Geertz, 1973) and my own thoughts, feelings and non-verbal interactions (Mulhall, 2002). This included activities and observations that would have been missed had I just used verbal interaction. As part of my observations of individual experiences, I recorded environmental issues, such as body language, décor and room contents. These points are expanded upon in the case reports in Chapter Six and give strong indicators as to the individual experiences of living in three different care settings. Whilst I recorded copious field notes detailing my observations, the actual spoken interventions were brief with extended periods of silence. This led me to reflect later about why I had recorded some of the interactions in the way that I did and if I had been influenced by anything at the time, particularly in the care home where the care was observed to be less than adequate for all residents. Whilst I acknowledge that I was personally affected by some of the situations I observed, I believe that the rigorous manner in which I recorded my field notes, and at times the corresponding audio that conveys a similar emotive tone for corroborating evidence and adds validity as part of the process of identifying commonality in themes (Cresswell and Miller, 2000).

5.6.3 Digital voice recordings

Digital recordings were made during our time together, at other times I spoke my reflections as soon as I returned to my car. Additionally, I noted some of my observations aloud, such as to comment on the room temperature or on the increasing number of unopened DVDs in Andrew's flat. This enabled me to look at how words, pictures or actions were used in the context of the situation (Gomm et al., 2000). When beginning to analyse, I transcribed all words verbatim including expressions such as 'erm', 'yeah' and 'oh dear'.

I downloaded the recordings onto my computer after each visit and in preparation for transcribing. At times this required repeated listening to parts of conversation that were difficult to understand, although if I was aware of this at the time I would repeat what I thought had been spoken to seek clarity. I did not ask anyone to repeat themselves to avoid causing frustration to the participants, although this meant that some parts remained unclear. I included these sections in the case reports if that interaction, or expression, was considered relevant in giving insight into the person's experience.

5.6.4 Adapted communication

I was aware before commencing Stage Two that not all of the participants may communicate verbally and I remained flexible, making sure that I got to know each person first. I was prepared to use Makaton (Walker, 2000) a signing vocabulary

development project for people with intellectual disabilities, or Talking Mats (Murphy et al., 2007) a speech and language therapy tool used to aid communication, or Boardmaker (Communications, 2002) colour communication symbols. I had previous experience and training in all of these areas. By adapting my approach, I was acknowledging differences in each person's ability, preference and individuality. I continued to work with them at the point they were at, rather than expecting them to only engage in verbal dialogue. Although I was aware of the importance of developing a relationship with each participant (McKillop and Wilkinson, 2004) I had not anticipated this process to differ so widely between each person.

Communication with Andrew, living on his own one-person flat, was verbal and relatively easy to understand especially in the early period of data collection. I did increasingly repeat his words at times to reassure myself that I had heard correctly, consistent with Sabat's (2002) notion of 'indirect repair' to check meaning although did not ask him to repeat if something was unintelligible.

Communication with Lucy, in the intellectual disability group home, began as verbal interaction and quickly moved to the use of the pictures shown earlier in this chapter. I became aware of her enthusiasm when looking at photographs and chose to build on this by introducing pictures, initially with little success until the 'right' style of picture was used for Lucy. Even whilst Lucy was incorrect in her initial recognition of my pictures as family members, I did not correct this. Instead, I changed the style of picture rather than cause any distress by imposing my view on what she believed

were her, happily shared, pictures of family members. It also served to remind me of the contested notion of ‘truth’ and altered sense of reality in dementia care.

Communication with Hannah, in a care home for older people, quickly became non-verbal and was developed as a result of her tactile approach towards me and her evident enjoyment of handbags. By incorporating Hannah’s non-verbal communication into the process I increased the amount of field notes and recorded my own speech to articulate what I saw. It was contact with Hannah that caused me most concern and I was often found in the car park, quite distressed, after my visits writing additional field-notes, for example about the disabling effect of her environment. On two occasions I was unable to leave the care home, once because of poor signage to the exit and on another visit finding myself stuck in a corridor between two locked doors without knowing the exit code, which was changed on a regular basis. On other occasions, I witnessed visiting family members in the same predicament.

5.7 Transcription

As fieldwork progressed, the recorded conversations were transcribed on an ongoing basis. This enabled me to identify themes from the data. I remained aware that we were still forming relationships during the early meetings and that the participants became more open and relaxed after our first few sessions together. I listened, in addition to observing, and I used Gee’s (2010) method of including pauses in, or between, sentences when transcribing, this meant that I counted the seconds and

included this in my transcription. I also added field notes recorded at each visit to the transcribed data. The case reports shown in Chapter Six are shorter versions of the full transcripts. The transcribing process can code pauses generally such as:

(.) short pause less than five seconds

(..) pause between 5-30 seconds

(...) pause longer than thirty seconds

However, I replaced each code with the exact number to show the seconds before a response, if one was given. This allowed me to note any changes over time, for example Lucy initially had pauses of less than 7 seconds but after eighteen months this changed to regularly between 25 – 60 seconds. In Andrew's case, the periods of silence extended from 5 seconds to an average of 30. These changes would not have been highlighted had I used traditional coding.

Although aware that being able to check my understanding with the participants can add validity, I was unable to do this due to the nature of dementia and did not revisit the response of participants on any given topic or conversation (McLeod, 2010).

Denscombe (2003) agreed that to do so might sensitise the participants to some of the questions or discussion, although he was not referring to research with people with dementia, intellectual disability or communication difficulties. I felt that the important information given was the first response or information that was volunteered.

5.8 Analytical process

Having introduced the method of analysis in Chapter Four: to develop case studies based on emerging issues for each individual, followed by cross case comparison, I will now explain the process.

5.8.1 Developing case studies

Although Silverman (2004) suggested constant comparison as a means of beginning to analyse large amounts of data I was not looking for commonality between cases at the first stage of my analysis, instead to highlight individual experience by looking for themes. Referred to by Mason (2002, pg. 18) as an ‘intellectual puzzle’ I began the process of sifting through the transcriptions and field notes. I firstly produced full verbatim transcripts which are not included in this thesis. Taking each case individually, and constantly returning to my transcript for each visit, I developed themes for all participants developed from verbal and non-verbal communication: expression of emotion, social interaction and the importance of relationships, experience in their home environment. Other issues were specific to individuals such as end of life care for Lucy.

I considered use of NVivo to import all of the data, and as an effective storage system, but decided on a longhand colour coding method. Steadily moving between data and concepts, although time consuming, gave me confidence that I had included all aspects of the person’s experience. I took the areas I had highlighted and imported

data manually into the table introduced in the previous chapter. Using this protocol, I built up the content of the case studies. A sample of this process is shown below with one of the tables and two of the emerging themes, based on my observation of Andrew's experiences. I noted for my own purposes where the information was stored on my computer (such as A1, A2 to link to the name of the document storing details of each visit) and if it was an observation taken from field notes (FN), rather than spoken data.

Theme	Presenting issue or incident
Interaction with home environment	<p>A1 Voluntarily shows me photographs of his family that are on display. Large piles of unopened DVDs in the hallway (FN).</p> <p>A4 DVDs have been sorted into piles, A shows me Them.</p> <p>A12 Room very dark, curtains closed, bulb very dim Heating on full – summer (FN).</p> <p>A15 New medication dispenser that A shows me.</p>
Non-verbal communication	<p>A6 Falls asleep, says has been watching DVD during Night. Tapping quickly on his leg as tries to remember .</p> <p>A14 No staff timetable on notice board this week (FN).</p> <p>A17 Keeps removing hearing aid and pulling at ear (FN).</p>

Table 11 Developing case study content.

Typically with case studies the balance of description over analysis sees a 60:40, or even 70:30, split (Polkinghorne, 1995). A rich description of each case is presented in my case studies including details of actions, interactions and my perception of experiences. Miles and Huberman (1994) suggested that to put together lengthy case studies could be problematic as there was no set formula for doing so. Consequently, official documents or paperwork are often included in case study research. This was not something that I used, as this would not help to convey individual experience at

that point in time, nor would it be the participants' own views. Over reliance on documents has been criticised in case studies (Simons, 2009) and I did not keep a database of additional material as Yin (2009) recommends, such as care plans.

5.8.2 Cross case comparison

After writing the case studies, which are included in the following chapter, the next layer of analysis was to look for any commonality between the three participants and identify factors that impacted on experience. Taking the broad themes used to develop the case studies, I then went back to the data to look in more depth at areas of commonality. This gradually built up to become the series of conceptual and practical emerging issues that are presented in Chapter Seven: the lack of a shared diagnosis, the extent of evidence of sense of Self, the importance of relationship-centred care, my observations of the role of staff and the role of adapted communication. An extract from the table that helped me in this process, as recommended by Yin (2009), is shown here to demonstrate the process.

Commonality	Andrew	Lucy	Hannah
Self 2 (positive or negative emotional characteristics, evidencing can/can't do)	Physically smart in appearance. Visibly pleased remembering details of football matches. Expressed dislike of college and preference for resource centre. Visibly distressed talking about dad's illness. Liked watching mice in his room.	Took pride in showing me possessions in room. Does not like attending day centre. Held arms out smiling when I arrived. Touched hair when I admired it. Expressed choice over use of pictures. Chose to look at family photographs. Liked 'getting it right' when we looked at pictures.	Ill fitting clothes that H kept pulling at as if annoyed – not sure if they were hers. Likes handbags, enjoys looking at contents and carrying around with her. Held out her hand on my arrival. Body language disorientated when staff moved her quickly to another room.

Table 12 Commonality in cross case findings.

The example I have used above is Self 2: where I have evidenced just some of each person's ability to express positive or negative emotions in relation to themselves. In this way manual analysis enabled me to develop a multi-dimensional account of individual experiences that incorporated more subtle changes over time, in addition to those more apparent such as communication changes. I actively constructed and reconstructed meaning in the experiences that I observed.

5.9 Leaving the field

It became apparent that, despite the range of literature on longitudinal research (Menard, 2002; Holland et al., 2006) the longer the amount of time spent in the field, the less guidance in literature there is for withdrawing. As a result, some of my actions were based on instinct and what felt the right thing to do. This included leaving my contact details with the person and with a staff member. I bought each person a card and gift at my last visit in the hope that this would symbolise an ending.

Due to some of the less than satisfactory care that I observed, especially within the care home, I had concerns when I knew I would no longer be visiting. This was an issue that I raised in supervision where I discussed my options as a student and a researcher. It proved to be a dilemma often seen in research where the boundaries become blurred between staying in my role as researcher, whilst at the same time being aware of a neglectful situation. After discussion, and after reading the most recent Care Inspectorate report for that particular care home, I realised that the areas

I had concerns over, such as mealtimes, had been noted in the recent inspection. This was not specific to the resident with Down syndrome and was seen across all residents. Additionally, I spoke to staff on two occasions and asked that time be spent with the participant at mealtimes, rather than assuming that she did not want to eat.

Separate to the research, but before the end of the research period, I arranged to facilitate a training session on intellectual disability and dementia for speech and language therapists in the health board area of the care home. Whilst this was a general training session, with no mention of my research, I endeavoured to make sure that those attending understood more about dementia in people with an intellectual disability and knew what to look for among their clients in different locations of care.

5.10 Summary

In this chapter, I have presented an account of how flexible and reflexive methods of data collection were introduced to develop and analyse case studies. A flexible approach was essential in order to take account of changing needs, and verbal capacity, as dementia became more advanced. This reaffirms the lack of an existing evidence base on conducting research with people who have Down syndrome and dementia, and the subsequent importance of adapting methods to enable inclusion in research. In my research new, or unexpected, situations were seen as opportunities not threats. For example, the decrease in verbal communication was accepted and prepared for as part of determining my research methods to understand individual

experiences. This allowed me to view and interpret people's everyday lives in a way that was meaningful for them despite this shift in ability to communicate verbally. I have evidenced awareness of my own role in the process, whilst ensuring that the three participants remained at the centre of the research.

It will be reinforced in the following chapter that meaningful communication was possible even into the end stages of dementia and, in two cases, long after verbal capacity had ceased. Despite their diverse situation, different accommodation settings and different communication methods, evidence of social and cultural marginalisation was evident in all settings to varying degrees, with the process of continuing exclusion remaining unquestioned. I explore the impact of this in Chapters Seven and Eight, but firstly present the individual case studies.

CHAPTER SIX

CASE STUDIES

6.1 Introduction

This chapter presents the experiences of the three participants based on three years of fieldwork from 2006-2009. Firstly, I present some context for each participant to explain their situation. I then focus on the themes identified from my data to present an overview of their experiences. In doing so, I have recorded the experiences thematically rather than chronologically. Some incidents or exchanges were noted repeatedly over the three years of data collection although are included once in the case study, such as conversation with Andrew about football and DVDs and poor support for Hannah at mealtimes in the care home.

Andrew's experiences are presented first. He experienced increasing isolation, not necessarily as a result of living alone, but due to an apparent lack of interventions that may have assisted him in the lifestyle he wished to maintain. Lucy's experiences are then presented, giving insight into living with dementia in an intellectual disability group home. Hannah's experiences conclude this chapter by highlighting the difficulties she had in the alien environment (to her) of a care home.

The concepts of narratives and communication are integral to this chapter and I acknowledge that the logical and clear way in which the following case studies are presented belies the ‘frayed stories’ (Taylor, 2010) of people with dementia, where there is an increased inability to relay stories in a conventional manner. The accounts of each individual are, by necessity, my own subjective views. Although enabling interaction, I was primarily an observer and listener in the research process, something noted by Taylor (2010) as inevitably affecting my emotions.

I have focused on creating opportunities for engagement within constraints that usually make such participation impossible. The stories are not mine; by offering a structure that incorporates shifts in time as dementia progressed I am offering insight and interaction into specific individuals in different locations set against lengthy periods of silence. Although the extent of the periods of silence cannot be fully conveyed in each case study, it should be remembered that, in the context of developing a relationship with each participant, we spent much of our time sitting in, what felt like, a companionable silence with Lucy and Hannah often holding my hand.

6.2 Case report A: Andrew

6.2.1 Background

Andrew is a tenant at G Housing Association, a registered provider of care for people with intellectual disabilities in Scotland. His accommodation is a ground floor, single

bedroomed flat in a city centre block. Other tenants with an intellectual disability live in single or shared flats in the same three-storey block, alongside privately let and council rented flats. Staff provided support on weekdays from their office base in the same block.

Andrew and I met on thirty-six occasions in his own flat between October 2006 and January 2010. The average length of each visit was fifty minutes. Prior to the first visit I had known Andrew for approximately eight years. He had been a regular visitor to the office of Alba to attend groups, or to call in if he was passing. He had not visited voluntarily for around three years. Andrew was forty-three when I started visiting him. He was five feet tall and dressed casually, always taking care over his appearance. He was diagnosed with dementia, believed by his father to be Alzheimer's disease due to a family history of the disease, at the age of forty-one. This information was provided in the Stage One postal questionnaire. At forty-one he was younger than others with Down syndrome who were diagnosed at an average age of 54.4 (Tyrell et al., 2001). Andrew grew up in his family home with both parents and his older siblings. It was always his, and his parent's, intention that as an adult he would move to his own accommodation and live as independently as possible. This became a reality at the age of thirty when he moved into his flat. He had remained in the same accommodation for thirteen years when I started visiting him.

6.2.2 Communication

Our primary method of communication was verbal, based on Andrew's ability and willingness to engage in conversation. Despite this, Andrew's clarity of speech was poor. His stammer increased over the three-year research period and his speech deteriorated. This made it difficult to understand all that he said, even when I had become very familiar with his speech pattern. There were regular pauses in our conversation lasting between three and thirty-nine seconds. Andrew only answered a question or continued a line of conversation if he wanted to. If not, or if he felt unable to answer, he would change the subject. This would often be after some long pauses.

Researcher: What did you see in New York?

eleven seconds

Andrew: Eastenders isn't on tonight.

Body language was an indicator of how Andrew was feeling. He showed increasing frustration at not being able to find the right words as the visits progressed.

'*Think...think...*' was often spoken during the first year. After nine months this changed to tapping fingers gently on his leg. It progressed after fourteen months to tapping firmly on his leg and chewing hard on the fingers of his other hand at the same time.

Andrew was visibly more alert, and there were shorter gaps in the conversation, when he spoke about his interests of football and movies. In 2006, when we were speaking about his favourite football team, Andrew looked away from me and whispered as if speaking to himself or thinking out loud. He recited results of matches from 1985 to the late 1990s concentrating hard, speaking slowly, often stammering over some words and mostly unintelligible. This continued for eight minutes, four seconds while I sat silently. After this time he appeared to become aware of me again and turned back to face me smiling. Andrew appeared to be pleased that he had remembered so much. Whilst to the casual observer this may appear to be inappropriate behaviour or self-talking, it was in context of our previous conversation. It was also a topic Andrew had always been very familiar with and he was referring to a time recalled from his longer-term memory.

He maintained a good long-term memory for facts and figures if they related to topics of interest to him, such as football. He asked me how old I was when I got married, how old I was at that time and instantly worked out the number of years that I had been married. He was also able to work out the days that birthdays would fall on after a leap year. The same behaviour occurred in 2008, when he began reciting a children's rhyme '*Remember, remember the fifth of November*' although Andrew recalled it using the words '*Remember remember the first of September*'. The same body language was displayed as the football example with Andrew looking away from me and concentrating on what he was saying despite this being a much shorter recital lasting for just nine seconds. Andrew was pleased with his recollection, which was again in the context of the conversation as this particular date in September had

just been referred to during the previous exchange when he asked me the date of my son's birthday.

For most of the research period Andrew spoke in short sentences of two or three words, although demonstrated a good use of grammar and spoke with eloquence even within his shorter sentences, a trait that he had before he had dementia.

Deterioration in his functioning and health towards the end of the research period resulted in a corresponding deterioration in his speech. I then became aware of an increased emphasis on his body language as a result of spending a lot of time with him and being able to recognise subtle differences. I grew to realise that it was important to allow thinking time as a natural part of the conversation. Had I tried to fill the sometimes long gaps in conversation, there is a possibility that Andrew would have stopped talking to me if he was not allowed enough time to respond.

Andrew's speech was harder to understand when he told me about his father's failing health. Similar to when he was tired, it became difficult to understand and his stammer increased. Andrew did not associate the lack of mobility on one side of his father's body with a stroke. During the period of his father's illness, visits to Andrew produced the most spontaneous questioning of the research period. He looked for explanations of what it meant to have a stroke, why his Dad couldn't move on one side of his body, why he was unable to speak and why Andrew could no longer visit him every weekend.

Andrew: One of his arms [pause] one of his arms is not [holds up his left arm], one of his legs is not [holds up his left leg].

Having this conversation, with my explanation of why his father was experiencing these changes, made a difference to Andrew's visibly high level of distress.

Andrew: Is that it? Is that why? [Surprised expression then visibly relaxed]

Andrew understood after I explained to him that his father's change in appearance and functioning was linked to the stroke he had just experienced. He then changed the subject and his body language appeared much more relaxed. Other occasions when speech became inaudible were linked to tiredness, with longer pauses becoming increasingly common although responses were still given eventually. I asked him to repeat something if it was inaudible, which he always did. On seven occasions, Andrew fell asleep during my visit. He admitted to often watching DVDs during the night.

6.2.3 Experiences within care setting

Andrew lived independently and took pride in maintaining his own tenancy. His choice was to remain in this flat long-term and during the research period there was no suggestion that this would change. It is likely that Andrew's family would have a large say in any future accommodation and it was his family who, with Andrew's agreement, had secured his position with G Housing Association.

Andrew's personal preferences in the flat were evident. Although the décor and furniture was standard issue of the Housing Association, he had football posters and family photographs on the walls and doors. His choice of entertainment was evident with a large television set, DVD player and many hundreds of DVDs visible all around the flat. Andrew regularly bought DVDs that remained unopened for months in their seal wrap. This may have been out of habit, if a trip to the shops became associated with buying more, or it may have been an area where he was able to exercise his own choice, not dictated by anyone else.

Staff provided support on four weekdays from a nearby office base, a system that had been in place since Andrew moved in. The emphasis remained on minimal staff intervention and promoting independence. Examples after a while, such as the overwhelming heat of the radiators turned up high all summer and his curtains closed all day leading to poor lighting in the flat, suggests that more appropriate support could have been provided as dementia progressed.

Andrew: It [radiators] goes off at night, it cools down then.

Attempts appeared to have been made by staff at non-technological environmental adaptations to Andrew's accommodation setting. This may have supported the principle of ageing in place but was not reinforced or monitored for effectiveness or flaws. Tools used to aid Andrew's memory and improve communication included a wall calendar hanging up in his kitchen. With Andrew's permission, I always wrote on this to show when I would next be visiting. Despite this, Andrew did not always

remember when our visits were and often forgot that I was going to see him. His calendar for 2007, bought by his father, was too large to fit in the space on his wall and was not used for a number of weeks at the start of the year until staff put extra holes in to enable it to be hung. The calendar for 2008 and 2009 continued to be too large and consequently often fell off the wall.

A large telephone with easy to read numbers was in Andrew's living room, although he seemed unclear of how it should be used.

Researcher: I think you have a message [message light is flashing].

[Field notes: Andrew picks up receiver, presses a few buttons and shrugs his shoulders. Puts the phone down again].

A similar situation was seen with Andrews's mobile phone. He was very keen to show me this and for me to put my telephone number into his phone. He knew how to work the mobile phone using the names put into his contact list by family or staff. I called Andrew on his phone before I went to see him, to check if it was still convenient, but he did not answer his mobile number. Although Andrew liked the idea of having a mobile phone, he did not remember to charge it so was unable to use it.

Researcher: Do you still use your mobile phone?

Andrew: No, it doesn't work.

Researcher: Oh what happened?

Andrew: Dunno. [He went to get it and showed me]

Researcher: Do you have a charger?

Andrew: Dunno.

There were a number of framed photographs around the living room. After a family occasion or holiday, Andrew would show me photographs that one of his siblings had sent to him. Sometimes the name of the person, or people, would be written on the back which Andrew would look at when he showed me. Names of places or excursions were not labelled in the same way, leading to a frustrating time when Andrew was showing photographs from his holiday to New York and could not recall, when looking at photographs, the names of places he visited, such as Ground Zero and the Statue of Liberty. Photographs of large groups of people at family gatherings were not labelled either and were subsequently quickly passed over to look at the next photograph, without any discussion.

Further efforts at pictorial adaptation to the environment were noted in early 2008 when a staff rota was displayed in the kitchen showing the name and photograph of the staff member working on a particular day. This was changed on a weekly basis. A month later, I noticed a number of changes on this weekly rota with names or photographs crossed out. There were frequent staff changes that did not find their way onto the pictorial timetable. The timetable was consistently wrong showing discrepancies between staff photographs and the actual staff member who was on duty.

Andrew: Sometimes face and different name or the name but different face [laughs]

Researcher: so you don't know who is going to walk in the door?

[Field notes: Andrew shakes head no].

In mid-2008 the office printer at the Housing Association was not working and although the staff rota had been put on the wall for that week, the pictures and text could barely be seen. A checklist was displayed on the fridge door later that year. This was for Andrew to tick for 'shower, teeth and feet' on three days of the week. Andrew was not sure why there were only three days in the week. The list was text with no graphics. Although Andrew did not ever complete it, the same checklist remained on the fridge unused for the duration of the research.

Andrew: I tick that myself, I don't know why.

Andrew's flat was usually quite cluttered as a result of his ever-increasing DVD collection, newspapers that he bought daily and sometimes dishes on the floor or table in the living room. The exception to this was after mice had been discovered in Andrew's flat.

Although he confirmed that traps had been bought by staff, Andrew did not seem to understand why he should not feed the mice, although he was clear that he had been told they were '*not the kind of mice you can keep*'. He repeated this more than once as if it was something that has been told to him.

Andrew: What do you call them? The kind you can't keep?

Andrew was not concerned by the mice, quite the opposite, as he suggested that he enjoyed them being there and was aware of their presence before staff and neighbours noticed, and acted to remove them.

Researcher: Did you get a fright when you saw one?

Andrew: No.

Researcher: Do they come through the night or day?

Andrew: Err night I think.

Researcher: Did you see them?

Andrew: Yeh, when they are in my bedroom.

Researcher: Don't you mind?

Andrew: No, I watched them in my room.

After the discovery of mice, the flat was at its tidiest with nothing on the floor, very little on the lounge table and only one plate in the sink. Andrew acknowledged that staff had cleaned and tidied the flat for this reason, although said that he usually did this himself.

Andrew: I do it all, can't stop.

eight seconds

Andrew: If I stopped housework.

four seconds

Andrew: No use at all, how? [Why].

Researcher: I don't know.

Andrew: [Laughs] I'd get evicted.

6.2.4 Relationships and observed interactions

Andrew's contact with his peers was less straightforward. He spent time, and possibly identified more, with others who had an intellectual disability. A further indication of Andrew's loneliness was witnessed in May 2008. On my arrival, the chair I usually sat in was occupied by an enormous teddy bear with two ties around its neck. Andrew had bought this at a charity shop.

Researcher: What made you buy a teddy?

Andrew: Company.

Researcher: Is that ties round his neck?

Andrew: My ties (Looks proud).

Researcher: Did you put them on him?

Andrew: Yeh.

Researcher: That was nice of you.

[Field notes: Andrew smiles, looks pleased, moves teddy to the floor so I can sit down].

The teddy bear remained a permanent fixture and was seated in the chair on every visit thereafter, sometimes wearing different ties or scarves. Andrew made it clear

that he was aware the bear was not real and could not communicate back to him, but he enjoyed the feeling of having something that he could talk to.

Andrew: Sometimes I talk to myself so I talk to him instead.

Researcher: And he won't argue will he?

Andrew: [Laughs] No.

six seconds

Andrew: I don't argue with him.

seven seconds

Andrew: Doesn't tell me what to do [Laughs].

To anyone not aware of this, it may have appeared evidence of psychotic behaviour or even hallucinations. It may have been attributed to either having dementia, or to having an intellectual disability, rather than seeing it for what it was - loneliness.

The issue of meal planning is connected to independent living and staff support, where the emphasis is on Andrew developing and maintaining skills. Whilst this is laudable, and fits many of the guiding principles of the social model of disability, it must be remembered that Andrew had diminishing capacity, despite his willingness to maintain long-held activities such as his weekly shopping. I usually arrived at Andrew's flat in the early evening at his request. He often said that he had not had his tea although on occasions a plate was in the room with cutlery and a smell of food. In April 2009, I asked Andrew what he was having for tea and he opened the door of his small freezer. There were six boxes of ready meals, all chicken curry. He

did his own shopping, but it was unclear if there was support for dietary and nutritional needs. By only buying the same ready meal for every day of the week this suggested that Andrew was becoming confused when shopping and only buying one thing that he recognised, or liked. It also suggested that his relationship with staff, and the support provided, had not changed as his ability to shop for himself decreased.

Andrew became agitated and frustrated at his own lack of memory, which increased over time. By year two there was a noticeable deterioration in his ability to remember individual words such as '*day*', when talking about an open day at the bowling club, and '*Alzheimer's*', when talking about his mum. As a result, I suggested shorter sessions that stopped when Andrew became tired even if this was after just fifteen or twenty minutes. It was not evident that staff intervention changed as dementia progressed, as the same pictures and signs were on display although not used by Andrew.

There was a marked improvement in his speech in 2008 when Andrew started taking Aricept (medication for Alzheimer's disease) and Levothyroxine (medication for thyroid) every day at the same time, using an automatic pill dispenser. However, the benefits noted were time limited and a further decline was noticed within ten months. It was not clear if the improvements were as a result of regular Aricept or regular Levothyroxine, or both.

6.2.5 Reflections

The first time I visited Andrew in his own flat I felt nervous even though I had known him for a few years and I expected him to remember me, which he did, although out of context he was not initially sure where this was from. Andrew was the first person I visited during the research. I worried that the reality of my chosen method, allowing people to talk (or not) about whatever they wanted, may not work in practice and what I might do if the 'or not' scenario proved to be the reality. I wondered if a more formal structure using fixed questions may have provided a safety-net that I could have fallen back on. By the end of the session I felt reassured and pleased at the opportunity that I saw opening up before me to observe and really understand some of the day-to-day support issues faced by Andrew and, in time, the other participants. It became clear that in his familiar setting he was relaxed and at ease with me being there.

Andrew did not see his health as part of his everyday life; his identity was not framed by it. He did not voluntarily mention it, or any difficulties with his memory, during our meetings. When talking about his family, Andrew was content to talk about positive experiences such as holidays or anniversaries. Having dementia or memory problems was not at any point the main focus of his day-to-day life or activities.

The time spent with Andrew required intense concentration on my part as his speech was difficult to understand. My visits came to an end when I started gathering up my papers and made arrangements to visit on another date, which we wrote on Andrew's

calendar. I was conscious that he would have been happy for me to stay longer. This was when I realised that Andrew may be blurring the boundary between what I saw as research and he saw as companionship.

Transcribing took far longer than the visits; I quickly realised that whilst working full time I would need to try and restrict my meetings with participants to one person a week. This meant visiting each person every three to four weeks which I tried to maintain over the three-year period, with exceptions over holiday periods when the gap was slightly longer. Carrying out research on this level was far more time-consuming than I had anticipated.

When considering what I learned from my time with Andrew, I know that I learned to respect the silence when sitting with a person who has dementia and that this can often bring about an appropriate response, albeit some time later. I observed the potential for a considerable gap between staff, who are trained to support independent living, having some basic knowledge about dementia care and their ability to individualise it in a person-centred way. The result was that any attempts at adaptation to Andrew's accommodation or daily living activities were virtually meaningless as they did not appear to be individualised enough, something that I found frustrating as there was potential to increase his quality of life with more appropriate support.

6.3 Case report B: Lucy

6.3.1 Background

Lucy was less than five feet tall with very short dark hair and big brown eyes. She smiled often which lit up her face, and was usually seen with her glasses half-way down her nose. She was visibly relaxed in the company of staff, although I did not witness her engaging with any of the other six residents, all of whom had an intellectual disability.

Lucy had lived in B House, a supported living group home for people with intellectual disabilities, for six months when I began visiting her. Her diagnosis of dementia had been made eighteen months earlier at the age of fifty. The manager of B House had completed the questionnaire in Stage One of the research. B House was a church-run establishment situated on the outskirts of a small town. Each of the seven tenants had their own room, with a shared living and dining area and shared bathrooms. Originally living in a long-stay hospital since she was a young girl, Lucy left this institution when it closed in 1999. This led to a move after twenty-one years to accommodation with the same service provider as at present, but in a group home with an upstairs bedroom. She subsequently moved to her current setting when her mobility deteriorated and prevented her from climbing stairs. Lucy's family remained in contact with her although lived in a different part of Scotland. Cards and gifts were on display in her room, at Easter and Christmas for example, and some of the family photographs we looked at were dated within the previous year. Lucy was

the only resident with Down syndrome and was the youngest in the all female house. No one else had dementia at that time and, when I started visiting her, I was told by staff that Lucy was taking medication for dementia and epilepsy.

6.3.2 Accommodation setting

Lucy's bedroom contained personal items such as toys, videos, photographs and a jewellery box, displayed on shelves. Lucy did not show any interest in the soft toys or an awareness of what they were during any of my visits, although she often was often watching musical videos when I arrived.

Lucy's television was on a chest of drawers at the same height as the bed and faced towards the bed so could be easily viewed if she chose. It was possible to get a feel for Lucy's personality from her choice of décor. This was very pink and chosen by her before she moved in, rather than her moving into someone else's room and inheriting the surroundings.

The small, supported living group home was well staffed with a presence in the living area at all times during my visits; sometimes up to four staff visible at any one time. There was a small office at the end of the main corridor, where only the manager appeared to spend any length of time. The laundry and kitchen were situated off the living area, so when staff were busy with other tasks they remained visible to residents and could talk to them at the same time. On each visit, there was noise of conversation or singing between staff and residents. This did not appear

problematic although potentially could be if Lucy, or any other resident, felt unable to ask for quiet time or space.

Lucy was visited on thirty-one occasions in her home between April 2006 and January 2008 with visits lasting an average of thirty minutes. When I started to visit Lucy in 2006 she was 53 years old with a diagnosis of dementia (type not specified). As Lucy and I had not previously met, the first visit was very much an introduction, confirmation that she was happy to meet with me and a chance for me to determine her method and level of communication.

When Lucy moved into B House she was able to walk slowly, but within months became dependent on the use of a wheelchair. Staff voiced concern that such a sudden loss of mobility may have been a reaction to another move in quite a short period of time. During my visits over the first year she appeared uncomfortable at times in the wheelchair, often slumped forward or sideways. After one year of visiting Lucy she was seated in a new wheelchair with padded seat, back and sides and an attached tray.

6.3.3 Experiences in care setting

In late 2006 and early 2007 Lucy was accompanied by two members of staff who supported her at all times at the nearby day centre, in an attempt to maintain her previous activity. This was a change from earlier years when she was more mobile and participated independently in a greater number of activities. Increasingly, this

became difficult to facilitate which, combined with Lucy's reluctance to keep attending, resulted in her ceasing to go out at all during most of 2007.

Researcher: Do you like it? [Day centre].

Lucy: No. [Pulls face].

Researcher: Oh dear.

Lucy: Loud.

Researcher: Oh dear is it noisy?

Lucy: Yes.

During my first few visits Lucy appeared quiet and shy and did not talk very much.

Mostly I asked questions and I was unclear initially of her understanding. Most of the answers were 'yes' or 'no' until we started looking at family photographs.

Lucy: My family [Points to photographs].

Researcher: Your family? Tell me.

Lucy: Christine.

Researcher: Is Christine your sister?

Lucy: Yes.

6.3.4 Communication

Staff informed me when I arrived for my first visit that Lucy liked the pictorial style of the information sheet I had sent to her and that she had been showing it to other

people. Staff had talked through this with Lucy before I arrived for the first visit and I also looked at it with her.

Lucy: That's you [Pointing to the picture, looking excited and laughing].

Researcher: Yes, is it okay for you to cross the paper to say that you are happy to talk to me?

Lucy: Yes [Crosses with pen in box].

Although Lucy initially communicated verbally, her speech was limited and declined as dementia progressed. Lucy's body language was very clear and showed enthusiasm when we started meeting. She sat forward in her wheelchair and was animated in her speech and arm movement.

Based on the success of the pictorial consent and information forms, I considered that this would be to be an appropriate way of planning for subsequent visits, particularly as Lucy's verbal capacity was limited. Pictures as a means of communicating were introduced on visit two. I prepared, and took, three different styles of pictures to determine if a different response was given to each. The pictures were printed from a computer and laminated. During the early visits they were placed on the bed, I also sat on the bed which Lucy sat next to in her wheelchair as there were no other chairs in the room.

The first group of picture shown were emoticons, (image 2 below), which were all coloured yellow with different facial expressions. Lucy recognised these only by

their colour and did not respond to any of the expression, for example happy or sad.

Lucy looked briefly and slumped back in her chair losing interest.



Image 2 Use of emoticons.

Researcher: I have some pictures here [Putting them in front of Lucy].

Lucy: Yellow [Looking at pictures].

Researcher: Would you like your glasses pushed back up?

[Field notes: Lucy pushes her glasses further up her nose].

Lucy: Yellow.

Researcher: This one is sad [Pointing to picture of crying].

Lucy: Yellow.

Researcher: Yellow, that's right.

Lucy: More yellow.

The second group of pictures, (image 3 below), were in the form of real life and still photographs. Lucy immediately pointed to the baby and also a dark haired woman who she identified as Christine (sister). Lucy recognised these pictures as real photographs and appeared to be trying to identify who they were, rather than selecting any other material from the content. Lucy did not react to any of the other

pictures apart from the woman and baby and appeared to lose interest, sitting back in her chair again.



Image 3 Use of photograph style images.

The third set of pictures (image 4 below) below were graphics taken from Clip Art. Lucy identified household objects and some parts of the body such as teeth and feet. She also kept going back to the pictures of a baby and a child. Through body language Lucy was engaging with the pictures, sitting forward in her chair and appearing visibly alert.



Image 4 Use of pictures.

Lucy: Happy smiles [Picture of false teeth].

Researcher: Yes a big smile.

Lucy: [Points to picture of baby] Baby baby baby boy at Christmas. [Getting quite excited as she spoke].

Researcher: It is a baby boy yes.

Lucy: Cup [Points to different picture].

Researcher: A cup of tea, do you like cups of tea?

Lucy: Yes.

Lucy: I know what that is [Pointing].

Researcher: Do you know what it is?

Lucy: Teeth [Laughs].

Researcher: False teeth, [laughs] they come out, have you seen people who that?

Lucy: Yes fork and plate [Different picture].

Lucy: Asleep, I got it [Points to picture of someone in bed].

There were gaps in the conversation of between three and twenty-five seconds. From the first month of visiting onwards Lucy associated my arrival with looking at pictures and photographs. During the second month, she looked for a picture of flowers which I did not have, but I arranged to include some the next time and did so. When looking at pictures, Lucy became very excited when she recognised and identified something,

Lucy: I got it, I got it, I got it.

During the fourth month of visits I noticed that some small photo albums had appeared on the shelf in Lucy's room. After asking if she would like to look at them,

Lucy enjoyed identifying some of the people in them. In particular, she was again drawn to photographs of babies and children. Lucy liked to give an answer and she especially wanted it to be the right one.

Lucy: Baby, I got it.

On one occasion she identified a photograph of Daniel O'Donnell (singer) as her brother, possibly as a result of wanting to '*get it*' rather than being sure of her answer. Lucy was at her most animated when looking at the pictures I took with me and the photographs in this album, although she needed to hold the photographs close to identify them. After five months, this particular album was not visible and Lucy did not know where it was. Another small album was found next to Lucy's television although this did not hold her attention. The photographs were smaller and often showed a large group of people. Names were hand-written on the bottom of the page but it was not possible to identify their relationship to Lucy.

Lucy: That's me [Excited and sitting upright looking at photograph].

Lucy quickly lost interest if she could not identify those in the photograph and sat back in her chair before moving back to look at the pictures I had brought instead. Here she correctly identified the image, taking more pleasure from the failure-free recognition of objects rather than looking at photographs and trying to remembering names. After a while I increased the size of the pictures as Lucy was holding them noticeably closer to her eyes.



Image 5 Enlarged pictures.

Lucy: Flower, I got it [Smiling broadly].

Although Lucy's sentences were very short, often one or two words with a delay in responding, I was aware that this did not mean that she had not understood. Anyone visiting the setting and speaking to Lucy, perhaps at a routine appointment or unannounced visit may not detect this due to her often very short answers. Lucy mostly communicated verbally during the first six months, late 2006 and during the first part of 2007, although non-verbal signals were still present. In July 2007, Lucy was slumped into her chair leaning towards one side.

Researcher: Are you okay? Do you need help to get up?

Lucy [Grins and pulls herself up].

Researcher: Does it get sore?

Lucy: Sometimes.

This interaction suggests that Lucy had been in pain or discomfort although had not verbalised this. In April 2007, when Lucy was in her new chair, I noticed that she

appeared much more comfortable. The wheelchair was padded at the back and had arms in addition to the seat.

After eight months, in late 2007, I noticed deterioration in Lucy's verbal communication with longer gaps in the conversation. Lucy seemed aware of this and she tried to fill the gaps much more with her more familiar and sympathetically spoken *'I know'*.

[Field notes: Lucy was slumped in her chair today and not moving about as much as usual. She tried to maintain our previous communication].

Lucy: I know.

twenty seconds

[Field notes: Lucy sighs and yawns, falls asleep, wakes up after twenty-five seconds and smiles at me].

Researcher: That's okay, you have a wee sleep.

[Field notes: Lucy smiles].

seventeen seconds

Lucy: Car [Points to pictures that were on the table].

Lucy: Blue.

Researcher: It is a blue car, well done.

[Field notes: Lucy smiles].

[Field notes: at first I was concerned that Lucy was answering 'yes' quite quickly to everything that I said. Every now and again she would expand on this and answer in the correct context such as 'yes it is' or 'yes it does'].

This reassured me that she was understanding the question or comment. Other measures of validity included affirmative non-verbal responses

Researcher: Have you had your hair cut?

Lucy: Yes.

Researcher: Lovely.

[Field notes: Lucy smiles and touches her hair].

A further example was seen in early 2007 after I had said that I was leaving

Lucy: I'll go there [Pointing to lounge area].

Over the next six months Lucy continued to recognise me and respond appropriately.

Researcher: Are you awake now; you were asleep last time I was here?

[Field notes: Lucy covers face and looks embarrassed, laughs].

On this occasion as I went to leave, Lucy leaned over towards me and pulled me towards her for a kiss goodbye.

Lucy: Come again.

Researcher: Yes I will if that's alright.

Lucy: I did it.

Researcher: Yes you did, you're a star.

Lucy: I'm a star, I'm a star, I'm a star.

In August 2007, Lucy fell asleep within a few minutes despite smiling and holding out her hand in recognition, which I took. Lucy was very drowsy and slept for five minutes, waking only as I moved my hand to go as she was so tired.

Lucy: I know.

Lucy: Pictures.

Researcher: Yes I have pictures. Maybe you are too tired.

Lucy: Baby (sleeps again).

[Field notes: after a few more minutes I leave the room quietly and alert staff that Lucy is sleeping. The manager said that they are asking the doctor to visit and she gave examples of Lucy sleeping both day and night, unable to feed herself or remember how to use a knife and fork].

The verbal interactions that I witnessed between Lucy and staff were often one-sided with staff chatting pleasantly and in a friendly manner, although asking rhetorical questions, not waiting or allowing her time to answer.

Staff member: Oh you like this don't you?

Staff member: Are you ready to go to your room? [Whilst pushing Lucy's chair towards the room].

Staff member: Lucy has been very sleepy today, haven't you? [Looking at, and speaking to, me rather than Lucy].

6.3.5 End of life support

When I visited Lucy in December 2007, her room was lit with low lamps and a fibre optic Christmas tree; it was warm and felt relaxing. A DVD was playing Christmas carols. There was a list in Lucy's room of family members and Christmas gifts to be bought for them. Lucy was in bed for the first time on my arrival, propped up with four pillows. She was jerky in her body movements and had no control of this. Lucy was not wearing her glasses. She wheezed a lot and had obvious difficulty in breathing. Lucy held out her hand to me when I entered her room although it was twenty-three minutes before she spoke, during which time I held and stroked her hand.

Lucy: Baby. [Smiled as if pleased with herself].

[Field notes: Although Lucy did not speak for a long time I felt that she knew who I was and she was aware of our previous interactions. She mentioned the content of the pictures I took with me even if I had not put them in front of me or her].

Lucy spoke again after this exchange although it was often inaudible and she did not seem to be looking for a response.

Researcher: where are your teeth?

[Field notes: unintelligible].

[Field notes: Lucy laughs].

Lucy: Oh dear. [Both laugh].

Although Lucy did not interact very much with me she seemed keen for me to remain with her. I was very aware of not wanting to stay if she did not want me to be there. Based on her body language, and positive manner towards me, I felt encouraged to stay.

Researcher: Will I go now?

[Field notes: Lucy pulls face, pushes her hand towards me reaching out her fingers, although I was already holding it and appears distressed].

Researcher: No? Are you sure?

[Field notes: as I left I spoke to a staff member who said that Lucy was mostly 'talking rubbish' now although I 'might get a yes or no from her'. She offered to phone me if Lucy was too unwell for our next visit].

That next visit took place in January 2008, when Lucy was again in bed. This time she made no attempt to speak and her jerky and twitching body movements were very pronounced and uncontrollable. She made sucking noises as if thirsty and was trying to clear her throat, although was not wheezing as much. She was able to smile at me, but not move. At no time did I see Lucy communicating with other residents although on this visit a fellow tenant wheeled herself into Lucy's room in her wheelchair.

X: Hello.

Researcher: Hello, how are you?

Researcher: What's your name?

X: Dinnae ken (I don't know).

Researcher: Are you a friend of Lucy?

X: Tired, sleepy that's what's wrong with her [Wheels herself out of the room].

Lucy tried to speak although I could not understand what she was saying.

[Field notes: Lucy inaudible].

Researcher: What was that?

[Field notes: Lucy inaudible].

two minutes, five seconds

[Field notes: Lucy inaudible].

Researcher: are you sore, are you in pain?

[Field notes: Lucy inaudible].

[Field notes: Lucy looks to be lying in an uncomfortable position in her bed, remains very twitchy and jerky in her arms and legs which she cannot control].

As I let go of her hand to leave, her facial expression looked worried, I stroked her hand and she relaxed again. Five days later Lucy died.

I was unsure what to expect as I approached the church where Lucy's funeral and requiem mass was being held. I had attended other funerals of people with an intellectual disability where there were barely a dozen people there and the service was rather impersonal. On this occasion, the church was almost full of family, staff, fellow residents and professionals who had contact with Lucy. As I entered, I was

given an order of service by a young man with an intellectual disability who told me that he lived in the group home that Lucy had lived in prior to her last move. There was a picture of Lucy as a younger woman on the front, and of her as a child with her parents on the back. The inside pages detailed the songs, hymns and readings that were to follow, with a statement that all were chosen by Lucy.

At the front of the church were personal items belonging to Lucy. These included her glasses that were forever falling off her nose, the red shoe musical box from the Wizard of Oz and her photograph album with family pictures. The service was personal and emotional, with stories from family members about Lucy's sense of humour, affection, smiles and her love of children and pink; a '*girly girl*' as was quoted at her funeral. This was affirmation for me that the person I had got to know with very limited verbal communication, and at the end of her life, was the same lady that everyone else in the church knew, including people who had known her for much longer.

6.3.6 Reflections

I felt a little guilty going to Lucy's funeral. I had only known her for a relatively short period of time, so was not sure whether it was appropriate or not. I felt slightly uncomfortable that I may have been going for myself as I felt upset at her death. This proved unfounded as I was welcomed by staff and other residents who recognised me and introduced me to Lucy's family. Reflecting afterwards, this probably was

confirmation that Lucy welcomed me as her visitor in a social capacity rather than as an academic researcher.

When writing Lucy's case report, I found it emotional listening again to transcripts of our meetings. Her voice and infectious excitement as she looked at photographs reminded me of how clear she was about her likes and dislikes. Perhaps it is because I was able to share some of her last months and weeks with her that her death had such an impact on me. Or perhaps it was genuinely getting to know, and like, her. Maybe I too was blurring the boundaries between social visits and research, although I am confident that I was always meticulous in my data collection; recording, observing and transcribing in addition to ensuring that Lucy was happy for me to be there.

6.4 Case report C: Hannah

6.4.1 Background

Hannah was sixty years old when I started visiting her in D care home, a small, sturdy lady who was not shy in sharing her opinions. I had known her, and her sister, for seven years when they lived near the offices of Alba. Hannah was taken to hospital with an infection in early 2006 and remained there for seven weeks as her sister was too ill for her to return home. It was here that dementia was diagnosed. After the intervention of her intellectual disability clinical psychiatrist, she was placed in D care home at the other side of the city. D was a large, privately owned

care home facility of six units, each with fourteen beds. It was a purpose-built premises situated on the outskirts of the city centre. Units were on the ground and first floor with three units (similar to wards) on each level. During the research period staffing appeared consistent with little turnover evident. The day-to-day running of the unit is the responsibility of a nurse manager with care assistants also on duty. In Hannah's unit, a minimum of two assistants were on duty at any time during my visits, both male and female. Hannah and I met thirty-three times between 2006 and 2009 with visits lasting between thirty and a hundred and ten minutes.

Hannah lived in an en suite room on the first floor. Her unit, as with the others, was accessed via a locked door from the central landing. On entry for my first visit, I was taken though a staffed entrance upstairs to the unit where Hannah was living. This was termed the unit for '*challenging behaviour and intellectual disabilities*' and was accessed through a locked door with a key pad. I was taken to the nurses' station to introduce myself. I passed along a dining area on the left hand side of a long corridor with a lounge area opposite on the right hand side. The long corridor leading to the nurses' station contained the residents' rooms on either side. Two doors displayed handwritten names on pieces of paper. One had a photograph stuck to it, although it seemed to be a photograph of the lady at that time rather than the recommended younger photograph that a person with dementia may more readily recognise. Small framed prints were positioned quite high on the wall along the corridor, with pictures of flowers and country scenes. The notice board in the corridor had staff names on it, all in writing with no photographs.

6.4.2 Accommodation setting

On my first visit the nurse took me to Hannah's room while she went to collect her from the lounge area. Her single room had three soft toys on the bed, the room was very tidy with few personal effects and the décor was the same as the corridor. There were small ornaments on the window ledge and a musical box on the bedside table. A single chair was placed underneath the television; this was very high on the wall in a corner of the room. It was not positioned so that it could be seen from either the chair or bed. Hannah walked into the room herself, although was helped by a nursing assistant who told me that Hannah had gained weight since she had moved from the hospital.

Before and after each visit Hannah was always seated in the lounge area. This was a large room with seats around the outside. After a few visits I noticed that residents appeared to have their own seats and were always in the same place, some became distressed if another person sat in 'their' chair. The television was always on in a corner although was rarely watched and at times had something on top that covered part of the screen. For example, at Christmas a reindeer soft toy whose legs dangled down obscuring the view, although despite this it was always turned on. No activities were present, although one resident had a doll that she always carried and spoke to.

In July 2008 and January 2009, when I was shown to Hannah's room to wait for her, the radio was playing loud, modern dance music. I assumed that this had been left on by care or domestic staff. When staff brought Hannah to her room they left the radio

on, appearing not to notice it, which suggested that this may be a common occurrence. Hannah's room was the first in the corridor, the furthest away from the nurses' station and almost opposite the lounge so the noise from here was heard very clearly. Equally loud was the noise from the dining room through the wall and the corridor outside, where I was frequently able to overhear dialogue.

May 2007

Staff member: [Shouting] Stop that.

Resident: No I'm not.

Staff: Yes you need to sit down.

February 2008

Staff to Resident A: [Shouting] Stop walking up and down the corridor, go and sit down and watch telly.

October 2008

Staff: Have a seat M until everyone finishes their meal [Considerable noise heard after this as M was made to stay in the dining room].

May 2009

Resident C: Where's John, when is he coming, where's John, when is he coming, where's John, when is he coming [Distressed].

Staff: [Loudly] I have told you C, he died three years ago.

Hannah's eyes and skin caused me concern, her eyes were 'sticky' and she had very dry skin. Between January 2007 and July 2009, Hannah did not leave the unit or the care home, she did not go outside or benefit from direct sunlight or fresh air.

6.4.3 Experiences in care setting

Hannah's relationships with staff were noted as being functional. In December 2008, I sat with Hannah in the lounge whilst nursing assistants brought in mugs of tea which were placed on low tables for some residents, including Hannah. The nursing assistant put plates down with slices of melon; some residents were given a fork, some were not.

Researcher: Cup of tea time I think, would you like a drink?

[Field notes: Hannah looks at the mug but does not attempt to reach it].

twenty seconds

[Field notes: Hannah smiles and lifts her fingers to her lips as if trying to eat but has no food in her hand. She appears confused and licks her fingers, putting her fingers in her mouth and sucking them].

Researcher: Would you like some help?

[Field notes: Researcher picks up mug and slowly takes it to Hannah's mouth where she opens her mouth for it and takes a small drink. Hannah looks at melon and makes pincer movement with her fingers whilst hand is in her lap then puts fingers in her mouth again].

Staff to Researcher: Would you like a cup of tea?

Researcher: No thanks.

The care assistant continued to give out slices of melon, no one is given any help to eat and only one of the thirteen residents in the room picks up the melon and eats with their hands. Hannah continues to make pincer movements and makes the action of eating from her hand but does not pick any food up.

Researcher: Can I help?

[Field notes; Hannah smiled at researcher and held out her hand. Researcher broke melon into smaller, bite size pieces and offers this to Hannah on a fork. She opens her mouth and accepts it, sucks and chews the melon then looks for more by opening and closing her mouth and putting her fingers in and sucking them again].

I continued to feed Hannah for twenty-five minutes during which time she ate two slices of melon after it was broken up and took a few sips of tea. Throughout this she held my hand very tightly. The care assistant re-entered the room and started to clear away dishes.

Staff: Have you finished? [To another resident who has not started eating, her plate and mug was removed].

The resident who had eaten was offered more but the plates were taken away from those who had not. One resident tried to pick up the melon but kept dropping it. The

care assistant asks if she wants her ‘*pineapple*’ (it was melon) and the response was ‘*I can’t*’.

Staff: Oh well never mind. [Takes plate away].

The care assistant came to Hannah and picked up the mug to help her drink. Hannah is expecting food, not liquid, and she spills the drink from her mouth, startled. The staff member wiped it roughly with a tissue and took the mug away, although it is not finished and I was clearly helping Hannah.

Staff: Do you want some more Hannah? [No answer so her plate is taken away]

Hannah and I sat in silence among the noise of the lounge with the TV loud and dishes being clattered onto a trolley as it was wheeled around.

Researcher: Was that good?

[Field notes: Hannah smiled and kept a tight hold of my hand. Even when I made a move to leave after another twenty minutes, Hannah was keen for me to stay. A different staff member came around to wipe everyone’s mouth whether they had eaten or not, she would not be sure of this as she had not seen].

One of the nurses spoke in an overly loud voice which caused some residents to pull back in alarm. The care assistants spoke more quietly, but to each other and often not

in English. They delivered the mugs of tea and soft drinks and cleared up again afterwards. No preference was requested and no cups were available.

6.4.4 Communication

Hannah did not speak although looked at me curiously when I entered the room for our first meeting in March 2007. I was unclear if she remembered me from her previous visits to Alba.

Researcher: Is it alright if I sit and talk to you?

Hannah: Show me [Reaches to my handbag on the floor beside me].

[Field notes: I passed my handbag to Hannah and she tried to open it, Hannah laughed and sang to herself, humming rather than using words. She passes the bag back to me].

Hannah: What's that? [Looking at my notepad].

Researcher: Paper [Holding it towards Hannah].

Hannah continued to sing and tap her hands and feet to her own tune, leaning forward in her chair and appearing interested in what I might say or do. She was very tactile, stroking and touching my arm and hands. She then became interested in the bag, which she initially thought was a dog before recognising it when she moved closer to it.

Hannah: Woof woof, that's a quiet one.

Hannah: That one. [Points at my bag and beckons it to go closer to her].

[Field notes: I move the bag closer and she laughs].

Hannah: It's a man's [Laughs].

[Field notes: Hannah picks up my bag which has short handles unlike her own bag which is over the back of her chair].

Hannah: I cannae (cannot) get it open [She fiddles with decorative studs as if trying to turn them. I show her how to open it].

Hannah: Ooh ooh [looks excited, sits forward in her seat and looks in bag].

Hannah: Smashing.

[Field notes: Hannah carefully removes everything from the bag, inspects and strokes it and puts everything back again, then leans forward and pats my knee].

The bag became the focus of our meetings for over a year, with Hannah always asking for it by holding out her arms and pointing, she would then put it over her arm proudly and look inside. During the first six months, Hannah also had her own bag which she took with her back to the lounge when I left. In November 2007, I noticed that this was missing; staff did not know where it was. Later that month I returned and left her a bag, this had also gone by my next visit and was not seen again.

On one visit when I entered Hannah's room it was very cold, it was a windy day and the window was open.

Researcher: Are you cold Hannah?

[Field notes: Hannah held out her hand to me, she didn't speak but had 'goose bumps' on her arms. I closed the window].

Hannah was not able to communicate her feelings such as warmth or cold and I came to realise that she was not able to verbalise pain either. In July 2007, Hannah was sleeping in the lounge when I arrived. I told the nursing assistant that I would return another day but he woke her up. Another staff member was called; they took an arm each and lifted her to her feet, then pulled her to her room. Staff spoke to each other in Polish while they did this. Hannah looked confused and disorientated when she was placed in the chair in her room. She held her hand out to me which I took and we sat silently for one minute two seconds until Hannah's breathing became quieter and less flustered.

Researcher: Is it okay if I stay a while?

[Field notes: Hannah holds my hand tight and laughs, a deep, loud laugh].

[Field notes: Hannah sighs]

Hannah: Right [Laughs and taps her leg singing a song] da da da dai dai da.

[Field notes: Hannah holds her stomach, yawns and looks around the room].

Researcher: Does your tummy hurt?

[Field notes: Hannah yawns and pulls down cardigan over stomach].

ten seconds

[Field notes: Hannah unintelligible].

Researcher: What did you say Hannah?

[Field notes: Hannah taps the chair arm and hums a tune, hand still on stomach].

This was not the only time that Hannah appeared to be in pain although did not verbalise it.

By summer 2008, Hannah was increasingly difficult to understand verbally and made noises rather than speaking words. She continued to laugh and smile, but equally clearly made it very obvious if she did not like or want to do something by pulling away and saying the one word that she still used 'noooooooooo' in her deep, loud voice.

Staff: Could she talk when she was a wee (young) girl?

Researcher: [Surprised] Yes, she could talk when she moved in.

[Field notes: Care assistant looked at me, didn't say anything].

The usual procedure for visits was for staff to tell me to go to Hannah's room and for them to bring her to me.

Researcher: Hannah, how are you?

Staff: She's fine, she's fine.

From February 2009, Hannah was in a wheelchair, on one occasion she appeared distressed when she was wheeled to her room to see me.

[Field notes: Hannah inaudible, high pitched noise].

Researcher: Hello Hannah, it's Karen.

[Field notes: Hannah peers towards me, doesn't seem able to focus well, squints, not wearing glasses. Slumped on one side in chair, doesn't look comfortable].

Hannah looked uncomfortable in her chair, but did not like it if I reached towards her to help her, as she always flinched. We sat quietly after the first few minutes when Hannah was initially quite noisy. My concern was that she may not have understood that I was there, especially in terms of consent. Although she was visibly relaxed in my presence and held my hand, it was the response to other questions or statements that affirmed her awareness of me.

Researcher: How are your teeth?

[Field notes: Hannah opened her mouth and leant towards me].

As time passed, and Hannah's dementia progressed, I was unsure if she would remember or maintain her interest in bags although this proved unfounded.

Researcher: Hannah would you like the bag?

[Field notes: Hannah inaudible - high pitched but not distressed, calm and smiles then screeches loudly, takes bag, strokes it].

Researcher: [Calming voice] That's okay.

[Field notes: I held out my hand to Hannah which initially caused her to flinch and pull backwards in her chair, starts shrieking when noise is heard from the corridor. She then reaches out to me and takes my hand].

Hannah remained interested in the bag for the duration of the visits, finding it relaxing and she appeared to enjoy touching it as she stroked the outside. For the last four months of my visits she stopped trying to open it and look inside, or remove contents, and appeared satisfied to just hold it.

Researcher: Are you okay?

[Field notes: Hannah looks at researcher].

Researcher: Do you want your glasses?

[Field notes: I cleaned and passed glasses, Hannah moves them towards her nose then stopped; I help guide to put them on, Hannah smiles then laughs. Hannah holds bag with two hands now tightly to her body, shrieks but not loud or distressed].

seven seconds

[Field notes: Hannah inaudible speech, laughs loud].

Researcher: Is it funny?

Hannah: Aye (yes).

[Field notes: Laughs and shrieks at same time, continues laughing and holding bag].

Researcher: That's better isn't it?

[Field notes: Hannah laughs, inaudible speech, tries to speak but can't form words, makes noises, not all shrieks but the tone and pitch is of a sentence without words as if trying to speak or sing. While she does this she pushes very hard on my hand and looks directly at me as if imploring me to understand].

It was apparent that the shrieking reduced, and then stopped altogether, after I had been there a while sitting quietly with her. Singing proved calming to Hannah and we

often sang together. She continued to join in although often with noises rather than words, not something that would have been identifiable to the casual listener. She held my hand during this time and at times hummed her own tune although very briefly.

6.4.5 Relationships and observed interactions

Although I did not seek to include staff or family as part of this research, I noted interactions that occurred naturally. One example was in January 2008 when I went to see Hannah as her sister was visiting at the same time. Both were in the day room and scones were being put in front of residents with a small amount of jam next to them. Hannah's sister knew me from their regular visits to Alba and had completed a questionnaire in Stage One.

Sister: I looked at a magazine you (the researcher) gave me once, one of the things said no white food on white plates because you can't see it.

Sister: Do you want it? [To Hannah pointing to the plate].

Sister: A bite, take a bite.

Researcher: Maybe she needs a bit of help.

Sister: What do you mean, she doesn't need help, she can do it if she wants.

Sister: She won't want it if she doesn't take it herself, try and you'll see [Points to scone].

Field notes: I broke a small piece of scone and took it to Hannah's mouth, which she opened and moved towards the food.

Sister: Well I never, you can do it for her, I never knew to do that. I just thought she would feed herself if she was hungry. You carry on hen (Scottish term of endearment).

I continued to offer food, which Hannah accepted, and tea, which she did not want, without speaking. Her sister tried to chat to Hannah at the same time, keen to tell her about, and show her, the Christmas cards they had been sent.

*Sister: Look at the wee (small) snowmen, where is the envelope from this one
Hannah, can you see it?*

Hannah focuses only on the food, after she has eaten enough she reaches over for my bag which she cannot reach on the floor. I pass it up to her; she laughs and holds it tight. Hannah leans forward towards me and makes unintelligible noises, smiles and laughs out loud.

Sister: Oh what's she saying?

Researcher: I'm not sure.

Sister: Oh jings, well you seem to be getting on with her.

[Field notes: Hannah leans to me again and laughs out loud. Hannah's body language is as if we are having a conversation, but without words].

Sister: Oh she does this a lot with you, it's the most I've heard her come from her mouth. She is trying to chat with you.

[Field notes: Staff member takes the scone away although it is not finished and she is still being helped to eat. Hannah lets go of the bag and leans toward researcher (inaudible)].

Sister: Well I never get that much from her (appears a bit resentful), well she's doing it again, why doesn't she do it for me? I'm only her sister after all.

I said my goodbyes and left at this point to allow them time together. This highlighted for me the importance of meeting basic needs such as eating and drinking and of meaningful activity, which for Hannah was the bag. This seemed more important than family news for Hannah at that stage in her illness, something that her sister had not been prepared for. Her sister still wanted to chat generally in the way that she would have done previously.

When I arrived in early 2009, I was later than my usual afternoon visit and the evening meal was about to be served. I said I would return later, but was invited to go to Hannah's room and help her to eat.

Nurse: You can wait or you take her to her room if you want.

Researcher (to Hannah): Is that okay?

Nurse: If she needs help.

Researcher: That's okay I can help her but only if Hannah is okay with having her dinner in her room.

Nurse: Yes it is okay but you will have to feed her if she needs help.

Researcher: Hello Hannah, is it okay to eat in your room?

[Field notes: Hannah smiled at me and held out her hand].

Hannah noticeably lost weight since I first started visiting her and looked frailer towards the end of the research period; at times she was escorted in by two staff and was unsteady on her feet, at other times she was pushed in a wheelchair. On this occasion, an apron was put on her and the food was brought through, macaroni (white) on a white plate with a spoon. Hannah made no attempt to touch the food or make a pincer movement. I noticed that Hannah had dried food on her face from earlier in the day. I touched her hand when she was looking in the other direction and she flinched and pulled away startled. The nurse told me that after recent speech and language therapy input Hannah now had her food thickened; the consistency helped her to swallow rather than choke.

Hannah put her finger in the food and then in her mouth, when I offered food on the spoon she opened her mouth for it. In between portions she continued to put her finger in the food and then in her mouth.

Researcher: Good girl.

[Field notes: Hannah inaudible, chews slowly, she only has a few teeth].

I continued to feed Hannah or help her to drink on every visit. The staff appeared to associate me with this and assumed that I would help her. This time, which could last up to eighty-five minutes, enabled us to continue interacting over the meal or snack time. I learned to anticipate, and understand, Hannah's reactions to food and drink to

know when she wanted more, or wanted to change from one to the other. It was also a time when Hannah relaxed and tried to chat.

[Field notes: Hannah making noise although in a 'singsong' way as if speaking a sentence but without words, relaxed and not looking for an answer].

Researcher: Are you having a blether? (chat).

[Field notes: Hannah laughed loudly].

Staff regularly called into the room to remove dishes before we were finished. On one visit in April 2009, the communal mealtime had ended in the dining room forty-five minutes before Hannah had finished eating with me in her room. My visits regularly lasted more than one hour. During the last seven months each visit began with Hannah initially continuing to shriek a lot when staff brought her into her room; she gradually became quieter and calmer until she made attempts at conversation, albeit without words. Equally, she was content to sit quietly holding my bag or holding hands. Her body language and quieter conversational tone, with noises rather than words, also reassured me that she was happy for me to be there.

6.4.6 Reflections

The loud, shrill noises that Hannah used may have disturbed other residents or been seen as inappropriate by others. I came to realise that they were always during attempts at communication or conversations; they were accompanied by facial

expression and in a tone that conveyed her emotions. I was not initially aware of this until I transcribed the recordings and combined this with field notes.

Despite Hannah being the least verbal of the three participants, she was the one that caused me the most extreme emotional reaction. For example, when I first witnessed food being removed with no attempt to help her to eat I tried to keep my emotions in check. I was very mindful of my role as a researcher and I felt unsure of what to do. Gradually, I gained confidence in my role in the knowledge that trust and communication between Hannah and me had become an integral part of our interaction. This was beneficial to Hannah as a research participant, although never was the isolation experienced by one of the participants more evident than in my observations in D care home, ironically the setting with the most support in terms of numbers of staff.

Hannah remained placid and calm when sitting with me, and I smiled and held her hand gently despite inwardly being angry and upset at the care she was receiving. The lady who loved carrying her handbag, enjoyed singing and had a deep, raucous laugh was being overlooked, and frankly ignored, by her carers in terms of her individual needs for communication, social contact and activities. I found this equally distressing when transcribing the sessions and reading my field notes. This was in the uncomfortable knowledge that this was Hannah's reality on a daily basis.

6.5 Summary of findings

As highlighted in Chapters Four and Five, the exploratory nature of my research led to flexibility and synthesis in my methods of collecting the data. The reports of my observations of three individuals who had Down syndrome and dementia give insight into their experiences after their diagnosis of dementia. The case studies reflect each person's struggle to make sense of what was happening to, and around, them.

Despite the differences in method of communication and location of care, the ability of the participants to share their experiences and give insight into their feelings was clear.

A key contribution of the individual case studies within this thesis has been to further understanding of the extent of unrecognised need among people with Down syndrome and dementia. Each participant was interacting with me, and those around them, from the perspective of a person with Down syndrome, not a person with dementia. This was alongside significant health and cognitive changes, but without an awareness of why these changes were being experienced. Attempts to 'fit in' or communicate as a person with Down syndrome would be meaningless, as the wider discourse around dementia, known by others, had already contributed to the process of marginalisation and exclusion.

This chapter has starkly highlighted experiences both contextually in different care locations, and temporally, to highlight the individual experiences of participants. In

the following chapter, I discuss commonality in these experiences based on cross case comparison of emerging issues.

CHAPTER SEVEN

DISCUSSION

7.1 Introduction

Based on my analysis of cross case experiences, this chapter discusses five conceptual and practice emerging themes from the case study reports. These themes are the lack of a shared diagnosis, the extent of evidence of sense of Self, the importance of relationship-centred care, my observations of the role of staff and the role of adapted communication. The impact of each has been to contribute to the overall experience of the participants as being one of further marginalisation. Firstly, I discuss each theme in relation to the three participants and to my earlier literature review. I then consider how, in the context of my findings, the social model of disability (Oliver, 1996) is not being fully applied to the situation of people with Down syndrome and dementia. Throughout the chapter, I raise concern at the potential for the institutional nature of life observed in the care home to be replicated in other accommodation settings and highlight areas in which further research is required.

7.2 Impact of the lack of a shared diagnosis

The first area of commonality to be addressed is the impact of the lack of awareness of the diagnosis of dementia. Early in the research process it became apparent that none of the participants were aware of their diagnosis, or why they were

experiencing changes. However, by looking for commonality I noted a range of opportunities where an explanation, if not sharing the diagnosis using the word 'dementia', may have been appropriate. I witnessed increased frustration evidenced through Andrew's lack of word finding and Hannah's shrieking as she lost the ability to form words, suggesting that dementia was impacting on both, although neither were aware of why. Lucy and Hannah were not able to explain, or talk about, any mechanisms used to cope with the changes they were experiencing. Indeed my observation of Lucy was of a passive acceptance of her situation. Andrew was the exception as he admitted that he had bought the teddy bear for companionship, knowing that he had become increasingly lonely. However, he did not associate this loneliness, or the loss of ability to use his central heating system or telephone with his own failing health. Instead, he struggled to maintain the tenancy that he had fought so hard to get, without understanding that there was a reason for these changes that was outwith his control. This partially replicates Lloyd et al.'s (2007) findings that people with Down syndrome and dementia were affected by the response of those around them, although participants in my research did not appear to be aware that there their physical health was changing as Lloyd et al. suggested.

Whilst societal perception was of people with Down's syndrome who also had dementia, each participant could only view themselves based on the existing stigma associated with having Down syndrome. This resulted in the transference of the process of marginalisation experienced in wider society due to having Down syndrome, into Andrew, Lucy and Hannah's individual, and at times institutionalised, experiences of care. My observation was of increased isolation and

increased silence, not only literally as witnessed when Hannah stopped speaking and interacting with staff, but also silence by being ignored. This was noted with Hannah at mealtimes when she was not assisted to eat. It was observed again with Andrew, where there was a belief that he would be able to maintain his living skills and manage his accommodation to the same extent as previously. Lucy was living in a group home with others who had no knowledge of her condition.

It raises a question originally asked by Hubert and Hollins (2000), which still requires further investigation in research. This is whether shared accommodation with a small number of others with an intellectual disability, who do not have dementia or knowledge of dementia, is a more or less favourable option than moving to a care home with others who have dementia, but are significantly older. Having observed at first-hand the experiences of participants in an older people's service and in intellectual disability services, I suggest that intellectual disability services may be in the best position to co-ordinate future care, due to the fundamental basis of their work across the lifespan of the person. Such services are most likely to have contact with the person before diagnosis. This avoids introducing a potentially younger person with Down syndrome and dementia to an older persons' service where staff have little, or no, knowledge of intellectual disability or potentially of dementia.

Although I sought participants for whom a diagnosis of dementia had been made in the previous two years, the rate of deterioration in physical health and verbal communication in both Lucy and Hannah suggested that they may have been at a more advanced stage when their diagnosis was made; alternatively their progression

may have been more rapid. The difficulty of making a diagnosis of dementia in people with Down syndrome has been discussed in Chapter Two. It is not possible to know if, had I met the participants earlier, more coping strategies would have been in evidence. I was informed that Lucy had chosen to stop attending her day centre which is consistent with an increased tendency to withdraw among people with an intellectual disability when faced with a situation that becomes too demanding (Hastings and Remington, 1994). It raises the question of how to address the issue of further marginalisation if someone is not aware of their diagnosis.

A challenge in dementia care generally is to provide appropriate post-diagnostic support and promote awareness that everyone is entitled to know of their diagnosis. A cultural process that addresses wider inequality is needed in order to acknowledge the human rights of people with Down syndrome to receive their diagnosis, as part of accessing appropriate support and treatment. ‘Top down’ rhetoric is needed for specific policy development and communication through all levels, but also a ‘bottom up’ approach based on actively involving people with Down syndrome; an overlapping of concepts as referred to in Chapter Two.

Each participant had a safe environment in which to live and be supported by staff. However, closer investigation using the Alzheimer’s Society (2012) definition of positive well-being in people with dementia suggests something different in relation to individual relationships. Key factors contributing to well-being are reported as:

- Exercise and mobility:

Only Andrew remained mobile; Lucy quickly became immobile after she stopped attending the day centre and soon used a wheelchair at all times, Hannah did not ever leave the care home and had to be helped to move by two staff members. She also used a wheelchair by the end of the research period.

- Eating well:

Andrew's diet became extremely limited whilst Hannah was not fed at all on occasions. I also witnessed her extreme weight loss during the research period.

- Dealing with hearing and sight problems:

Andrew showed me letters detailing regular podiatry and hearing appointments. Hannah had glasses in her room but I did not ever see her wearing them. Lucy always wore her poorly fitting glasses during my visits and held items close to her face to see them. She responded positively when I increased the size of the pictures, suggesting that the smaller ones had been problematic for her.

- Healthy teeth and gums:

Other than the sign on Andrew's fridge door to 'remember his feet and teeth' I was unaware of any intervention, as the appointments he showed me were not for a dentist. I did not know how often, or if, Lucy visited a dentist.

Hannah had teeth removed, with no false teeth as replacements. I remained unclear as to why this had happened although staff indicated that she may need more taken out at a later date.

- A good night's sleep:

Lucy and Hannah regularly fell asleep during the day although I was not present at night-time to observe how well either slept. Andrew openly spoke about his lack of routine and that he often stayed up overnight watching DVDs which left him tired during the day, sometimes falling asleep at college.

- Keeping warm:

Whilst the temperature in the group home and care home was regulated by staff, Andrew had the opposite problem. His heating remained on during the summer meaning that he experienced the other extreme of temperature; known to encourage sleeping and inactivity.

- Mental well-being:

Feeling valued is as important as physical health. I did not observe participants being included or asked for their opinions although, as I discuss later in this chapter, the ability to do so was still present. Staff spoke fondly to Lucy suggesting a warm relationship. Interaction with Andrew was not observed and in the care home with Hannah it was noted as being abrupt and

brusque. Mental well-being requires positive activities and stimulation, which was least evident for Hannah.

All of this suggests that the impact of not having information about their diagnosis may be more significant than initially appeared, both for the participant and for those who provided support. Despite day to day experiences not being formed by knowledge of their health condition, Kitwood (1997, p.82) found that when a person with dementia did not have their individual basic needs met, whether in terms of attachment, inclusion, information, or the issues included above, the result was 'depersonalisation'. This is a process that placed each participant in a negative position, creating withdrawal and social isolation. Whilst it has been most commonly written about in connection with institutional environments and dementia in older people generally, my findings have shown that this process of depersonalisation was evident among the participants with Down syndrome and dementia. This is consistent with a social constructionist approach when labelling is applied at an individual level to explain behaviour viewed as difficult. It was my observation that depersonalisation was due to the failure of others to recognise individuality, or support the recognition of retained identity. A lack of understanding of changed behaviour in people with dementia often leads to the label of 'challenging' without an understanding of what may constitute the norm for that individual. For example, Hannah was reprimanded by staff for taking someone else's handbag from the communal lounge area which caused her distress. Yet, as I learned through developing a relationship with her, in Hannah's sense of reality handbags were not

only an important feature, they were also an aid to communication and a means of social engagement with others.

On reflection, talking to the person with Down syndrome about dementia should be a primary consideration. This should not be viewed as an isolated discussion, but as an ongoing process. How it is shared should be based on the capacity of the individual to understand. This may mean that the word ‘dementia’ is not used, but instead an explanation given of the changes being experienced. Diagnosis may be made after dementia has already progressed in people with Down syndrome, but I believe that the post-diagnostic stage should still be seen as a crucial stage in future planning, as it is with older people generally. The diagnosis, or explanation, should be shared using consistent terms and a pictorial passport, or similar use of pictures or signs, if the person is familiar with this.

Currently, there is limited guidance on how to explain dementia to people with Down syndrome. The shortage of information available for staff and family carers increases the potential for stereotyping at an individual level. Until information is shared about the diagnosis of dementia, we are unable to position people with Down syndrome and dementia as an authority on their condition (Albrecht et al., 2001). This lack of sharing information about dementia with people with Down syndrome, if not the diagnosis itself, is a position that I am no longer able to defend having observed the impact that this had. If participants had an awareness of dementia I would also have evidenced a more typical phenomenological approach to understanding experiences, which seeks intentionality, or how far the individual is

conscious of something in relation to themselves. In reality, this remains an area of research that is still needed.

Among the general population there is recognition, in the early stages of dementia, that a diagnosis does not automatically mean that the person is unable to make a decision (Wenger, 2003) and indeed it is recommended in research literature, policy and guidance that communication is adapted in order to support this process (WHO, 2010; Whitlatch et al., 2006; Scottish Government, 2010). My findings show that this has not been extended to people with Down syndrome and dementia, despite awareness of the opportunities created in the general population. The second emerging issue from my cross case comparison relates to the emergence of relationship-centred care.

7.3 Importance of relationship-centred care

Coming from literature on chronic illness, rather than intellectual disability or dementia, is the notion that personhood is best understood in the context of relationships, with an appropriate balance needed between dependence, independence and interdependence (McDonald, 2005). Whilst an approach focusing on relationships may be a new way to support people with Down syndrome and dementia, it is not new to dementia care where Kitwood (1997) first emphasised its importance as part of his person-centred theory. He saw it as important in reducing the impact that I also observed of isolation and disempowerment, whilst being crucial in recognising retained ability.

Nolan et al.'s (2006) development of this relationship-centred approach into a 'senses framework', as introduced in Chapter Two, may have more to offer for people with Down syndrome as dementia progresses. Although developed as part of an approach to caring for older people, it maintains that the person, their family and those who provide paid care should all experience relationships that enable a sense of:

- security;
- belonging;
- continuity;
- purpose;
- achievement;
- significance.

This recognises the role and experiences of those providing, in addition to receiving, care. My findings suggest that for people with Down syndrome and dementia it may also be relevant to add a fourth element, that of friends (or a partner) who, depending on circumstances, may have had a longer, or more regular, relationship with the person than some of their family members. This will require a cultural change among intellectual disability services where the focus is typically on maximising independence in the long term, as observed with Andrew. I urge caution about this area of support typically viewed as good practice with people with intellectual disabilities; maintaining and supporting independence as a long-term goal. Instead, a person-centred approach should focus on maximising existing skills, rather than

supporting new ones after a diagnosis of dementia. This was evident in Andrew's situation where he struggled with some daily living skills. Due to ill health, Hannah's sister became less able to visit her yet no one took on this role to support Hannah. As a result, she did not experience the above 'senses' in the care home. Whilst it is not possible to say what Lucy's relationship with her fellow tenants may have been had she not had dementia, I took note of those I met at her funeral who identified themselves as friends from her previous accommodation. I spoke to many who identified themselves as her friends, although they had not seen her since she moved. Three had known Lucy for the twenty years prior to her first move, as they had lived in the same long-stay hospital before their discharge. They were not aware of why she had moved, only that they did not see her anymore. Their talk of shared activities, and the photographs that supported this in her albums, suggested that Lucy had previously enjoyed social relationships with others. Whilst reduced contact with others may have been Lucy's choice, her interaction with me suggested that this was something that she still enjoyed. It may have been that Lucy would no longer have recognised her friends as her dementia progressed, although having known them for a long time may have made a difference. To maintain the friendship would have required a proactive role by staff after her move, which was not observed. As this importance of relationships was identified by participants, and noted as part of my observations, I suggest that research is needed to further investigate the importance of maintaining relationships and a relationship-centred approach for people with Down syndrome and dementia.

7.4 Evidence of sense of self

As a result of my interactions with each participant, and by directly comparing their experiences, I witnessed the extent of the notion of Self (Sabat, 2002) in each individual, something not previously recorded in research literature about people with Down syndrome and dementia. Based on my findings, I suggest that the increasing lack of verbal narrative did not result in a loss of Self. This reflects the same findings as people with dementia in the general population (Kelly, 2010).

I noted through visual observation, in addition to verbal interaction, that all three participants expressed Self 1 (the concept of I) by locating themselves in relation to me, for example by showing a preference for what we did. This reflects their point of view, and the use of first person expression indicated responsibility for actions. For example, if communicating verbally this was through the use of 'I' or 'me' or the physical action of taking something. Sabat maintained that Self 1 remained evident through to the advanced stages of dementia. This was evident with Lucy who continued to associate my visits with looking at pictures until the end of her life, and long after she became unable to communicate verbally. Visually, Self 1 was evident in the response that greeted my arrival as I was greeted with smiles or a hug. As this was followed by an appropriate interaction as Lucy looked for the pictures, I was satisfied that this response was specific to me, rather than the welcome given to all visitors.

Self 2 (insight into physical or emotional attributes) was evidenced through the participants showing positive or negative characteristics about themselves. All participants expressed pleasure, pride or annoyance to varying degrees. In some instances this was non-verbal, whereas Sabat evidenced Self through verbal means. Andrew took pride in reciting footballs scores and showing me his college achievements, Lucy in 'getting it right' when we looked at pictures and Hannah in exploring my handbag and sharing the contents with me. I was able to reflect on how easy it would have been to overlook Self 2 without knowing the individual well, or spending time with them. Small details were recorded in my field notes that supported Self 2; Lucy touching her head when I admired her hair and Hannah opening her mouth when I asked about her dental treatment. Andrew was able to verbally express Self 2, for example becoming upset when talking about his dad's ill health. His own frustration at his increasing lack of word finding is further evidence of Self 2.

Self 3 (how people see themselves socially; their public and social role) was less evident as this required the co-operation of others, evidence of which was more limited in my data. During my observations, I did not observe staff creating opportunities for Andrew, Hannah or Lucy to express Self 3. Yet, Andrew's removal of the teddy bear to allow me to sit down, Hannah's 'conversation' using noises, body language and expressions when in the day room and Lucy taking pride in showing other residents that she had a visitor, were all evidence of Self 3. When interacting with me, expression of Self 3 was clear in all participants. This was due to

the enabling environment I created, where expression and the development of a relationship and communication were supported.

My limited observation of the role of staff was of ‘unrecognised Self’ in the people they cared for (Sabat and Harre, 1992). At worst this involved neglectful behaviour such as in the care home, at other times it involved withholding information about diagnosis and failing to acknowledge individual preferences, even as basic as a fondness for handbags. Cohen-Mansfield et al. (2006) showed that a poor recognition of the sense of identity in older people generally as dementia progressed led to feelings of distress. It is not clear if their research findings were connected to participants’ knowledge of their diagnosis, which was not the case for participants in my research, although it highlights the needs for individual recognition of identity and valuing differences in relationships and interactions (Balandin, 2011). By not acknowledging the presence of Self 3, the social construction of their identity and individuality became damaged for each person. If staff do not realise that someone is presenting themselves in a certain way, or respond appropriately, then the social identity of that person is weakened. Continued positioning of the person as incapable means that the opportunity will be lost to take meaning from experience and interaction.

I have shown that recognising where the person is situated, in terms of their sense of Self and identity in relation to others is important. This supports Hulko’s intersectionality claim introduced in Chapter Two; knowing where each person is located socially within their different identities and their environment. My findings

about experiences of Self in people with Down syndrome and dementia are consistent with those of Tuffrey-Wijne et al. (2009) when researching the experiences of people with an intellectual disability and cancer. Doctors did not make an assessment of capacity to understand how the diagnosis of cancer may be received by the person with an intellectual disability. Instead, they relied on the views of carers over decision making, treatment options and whether to share the diagnosis. As a result, interactions were limited in their potential for maintaining or improving well-being. The culture change experienced by those supporting a person with a diagnosis of cancer can offer potential for the future direction of support. Bamford et al. (2004) noted that, in the past, professionals giving a cancer diagnosis would typically have been poorly trained and emotionally unprepared. This has changed due to a range of guidance, training and advice for health professionals in how to break bad news around cancer, how to communicate with patients and offer more compassionate care. The changes recognise that cancer is not experienced in isolation; it affects family, friends and peers, similar to Hulko's (2004) positioning on dementia as impacting on shared identities with others.

7.5 The observed role of staff

A further area of commonality was in my observation of the impact of staff.

Although not directly including staff in Stage Two, I witnessed naturally occurring interactions between staff and participants. When transcribing, I was surprised at the extent of field notes on this issue suggesting the need for research that includes the perceptions of staff. Examples in my research included staff escorting Hannah to her

room on my visits, my arrival at the group home and being taken to see Lucy and when I observed the weekly timetable that staff had printed, often inaccurately for display in Andrew's flat. Observations suggested that Andrew appeared to be supported to live as independently as possible. Signs seemed to be the main visible attempts at support by staff, although I was not clear if they were also used prior to Andrew's diagnosis. Although confused at the 'shower, feet and teeth' sign on his fridge door, Andrew also found it amusing, '*aye, I've still got feet and teeth*' and was clearly unsure what the intended message was. In Andrew's situation, staff did not appear to step out of their familiar pattern in terms of support work. It is not possible for me to know if staff were aware of the different approaches required for dementia care, or if they lacked confidence in implementing new or different strategies. As noted earlier in this chapter, whilst maintaining previous skills is important for well-being and sense of Self, there also needs to be an awareness of areas where additional support is required as skills decline. I had to also consider, as an alternative interpretation, that Andrew, in his determination to remain independent, resisted seeking further support. I observed areas for all three participants where they increasingly relied on staff, something also noted in the general population for older people (Clare et al., 2008).

My observations of Lucy's interactions with staff were limited to moving her wheelchair from the lounge area to her bedroom for her meetings with me. When staff spoke, they were gentle in their approach and at times spoke to her as if she were much younger. This may have been as a result of her illness, or it may have been their self-consciousness as a result of my presence. The exception was in the

last few months during her end of life care when, although a caring and concerned approach was evident, staff spoke across the bed to me, rather than Lucy. She was permanently in bed at this point and was noticeably startled on a number of occasions when staff moved her to plump cushions and raise her in the bed, without first informing her of what they were doing. I was unsure of how familiar staff were with providing end of life care; this was reinforced at Lucy's funeral when two staff told me they had not realised how ill she was, or that her condition was terminal.

At times, staff were observed in a way that showed a lack of respect for the dignity of participants and threatened their sense of Self, particularly in the later stages of dementia when Hannah and Lucy were unable to respond. This lack of interaction, even in public areas, suggested a mirroring of their status as a person already marginalised by having Down syndrome. This positioning was transferred to their care setting. When visiting Hannah in the care home, staff regularly spoke to colleagues or to me, rather than directly to Hannah. At times, when speaking to each other, this was not in English and instead was in the first language of some of the staff, which was not understood by Hannah. The level of English language amongst the staff varied, with one staff member repeatedly calling Hannah '*him*' and another answering my question, '*will Hannah be having any more teeth taken out?*' with the response, '*I think she eats fine*'. Whilst staff were undoubtedly busy in such a large unit, with high care needs of the residents, a lot of time was spent in the day room with only the television as an activity. This was constantly on, even though it could not be seen from all seats. When staff were in the day room, I often observed them

working at the table rather than engaging with the residents; not an environment conducive to developing relationships.

My observations support Caddell and Clare's (2010) conclusion that the typical image of a person with dementia is of dependency and incapacity. This extends the 'Othering' witnessed towards people with a disability generally where labelling and stigma appear as a typical reaction (Traustadottir, 2007). An important part of my approach was that I had high expectations of the participants, as recommended by Goldsmith (1998), contradicting negative stereotypes. This also contradicts the views of carers who took part in Stage One, the majority of whom did not include the person they cared for in routine decisions. This was further demonstrated in the lack of a shared diagnosis. The combination of Down syndrome and dementia appeared to create a situation beyond the experience or knowledge of most staff. Although including the term 'double whammy' (Williamson, 2009) in Chapter Two, I now have concerns that this, and 'dual diagnosis', when used in relation to dementia in people with Down syndrome, will deflect from the individuality and specific issues of both conditions, that need to be recognised and addressed.

My observations suggest that, in the right circumstances and with appropriate knowledge, staff can transform opportunities by creating an enabling social environment; a further example of an area where more research is needed. Whilst I am not able to offer comment on why staff did not adapt their communication, research literature suggests that this may be a defence mechanism, against something that was not understood, or even that was feared. This is seen in the general

population when family members of people with dementia emotionally detach themselves as dementia progresses (Sweeting and Gilhooly, 1997).

Whilst people with Down syndrome and dementia are now increasingly present in society, due to factors identified in Chapter One, my findings suggest that they are being 'Othered' through a lack of recognition of their specific needs and experiences at both individual and policy level, resulting in further social and cultural marginalisation. Ang (1996) referred to this as 'inclusion by othering' whereas, rather than overtly excluding as seen previously, people in marginalised groups are now tolerated under the guise of inclusion. This leads to the expectation of compliance that I observed in all three care settings, particularly the care home, rather than embracing and understanding difference.

Looking to the literature for an understanding of the ways in which people moved towards greater independence shows that there has not always been clarity over what term independence means. Zola's (1982) recommendation for people with a physical disability was to encompass an individual's quality of life, taking into account the notion of risk. This brought about the change that saw services move from doing something 'to' a person towards planning and creating services 'with' them. My research suggests that the same course of action is now needed for people with Down syndrome and dementia. Despite the range of changes and developments that, separately, services for people with an intellectual disability and people with dementia have seen over the intervening decades as shown in Chapter Two, this has not extended to people with Down syndrome and dementia. For this group, we need

to revise the interpretation of independence, due to the progressive and irreversible nature of dementia. The overall premise of person-centred care is still relevant but needs to also reflect the changes and increased support needed when a person has dementia. In a different context, French and Swain (2004) recognised this asking ‘what’s so great about independence?’ about people with a physical or intellectual disability who felt under pressure to appear ‘normal’ and for whom striving for independence could lead to low self-esteem.

7.6 Impact of adapted communication methods

A further area of commonality between cases was the extent to which experience was influenced by non-verbal communication and the impact that this had on social interaction. At the beginning of the research period, I had expected to follow a more traditional route in terms of research methods and methodology. It became apparent when searching for research literature that these traditional routes were, in part, barriers to including people with complex needs in research. Most relied on verbal communication and required a level of cognitive ability that would remain relatively intact during the research period. Helped by the longitudinal nature of the research, I took time to determine how best to communicate with each person.

Incorporating silences was built into my phenomenological approach where I was recording description of events or actions. I was able to adapt my approach so that participants were not required to communicate verbally for some, or all, of the research period, reflective of Serrant-Green’s framework of incorporating ‘screaming

silences' (2010). The findings support my decision to follow the approach of Giorgi (1983) in that phenomenological bracketing, or setting aside my existing knowledge, was not practical. My adapted process required confidence in supporting people non-verbally, for example with Lucy after the first and second attempts at identifying appropriate pictures were not successful. At the third attempt, Lucy and I successfully started our individualised method of communication by discovering a style of pictures that was meaningful for her. Non-verbal communication remained important as she would hold out her hand to me increasingly over the period of the research. Lucy loved social interaction and this was never more evident than during my penultimate visit before she died when she was unable to speak, but still looked for pictures. Holding hands and being with her proved a satisfactory means of spending time for Lucy who smiled and kept looking at me, holding my hand tighter if I moved. Silence also featured in our interaction although Lucy would fill the silence with '*I know*' on a regular basis. This was always spoken in an empathetic way to me as if she was repeating a manner, and tone, that she had herself heard over the years. As Lucy's verbal ability decreased, my observation was of staff not looking for a response from her and quickly moving on if she did not reply immediately.

The range of non-verbal communication methods used highlighted to me the desire of each participant for companionship and social interaction. The reality I observed was the opposite. Whilst communication methods had the potential to be temporary due to the nature of dementia, my knowledge was gained from the relationships that we developed over time. I learnt about the individuals themselves, something that

was not temporary, as their personality and temperaments remained throughout the research period, even as dementia progressed. As a result, I am confident that I empirically grasped some of what each participant was experiencing. Ultimately, changing my overall research aim to focus on factors that impact on experience, rather than understanding the experience, gave valuable material and information in this under-researched area. During the research, I reflected on whether or not the experiences I observed may have been different had the participants known of their diagnosis, or known that they were ill. Indeed, this may have coloured their responses and perhaps even offered a more negative outlook, mirroring society's reaction to dementia and adding to the stigma already experienced due to their intellectual disability. However, the lack of studies with people who have Down syndrome and are aware of their diagnosis of dementia means that further research is needed before we can actually understand the experience of dementia with this group.

Hannah communicated verbally before she had dementia, although had limited speech when I started visiting her. Communication methods with Hannah were developed after the first few visits when I observed what she liked to do, and how she interacted with me, based on my handbag by touching and stroking the contents. She initially thought the bag (brown, barrel shaped) was a dog, *'that's not barking down there'* which caused her much hilarity. Hannah was not interested in what the objects inside the bag actually were; it was the tactile experience of touching them that she enjoyed. My concern in the care home was due to the potential for a reversion to the same institutional observations recorded by Oswin (1973) with the

television always on, the lack of communication with those who had more complex needs and staff not always speaking the same language as the person they were providing care for. Hannah held out her hand after the first few meetings and enjoyed holding my hand, although was not observed to have physical contact with anyone else. The exception to this was functional contact, when escorted to her room by two staff members, holding her arm at either side. As the amount of verbal interaction reduced, the hand holding appeared to become increasingly important as her means of physical contact. Similarly, Andrew hugged and cared for the teddy bear; enjoying showing me how well he was looking after it.

The examples in this section have shown ways in which communication and identity are constructed together. Both are shaped by where people live and how they are supported. Supporting inclusion in research was not an isolated act on my part. It was individualised and woven throughout the process, right from the beginning when I sent my photograph to each person. It then became about getting to know each individual and basing our communication on something that was meaningful for each person. For Andrew this remained verbal, for Lucy it was pictorial, whilst a tactile approach was appropriate for Hannah.

In developing my approach, I took more from research strategies with people who had dementia (Banerjee et al., 2009; Clare et al., 2008; Goldsmith, 1998) than from strategies with people who had an intellectual disability (Walmsley and Johnson, 2003; Nygard, 2006).). This is due to more research into dementia embracing reduced, and reducing, cognition therefore taking into account the need for changing

communication. Research with people who have an intellectual disability has undoubtedly made strides towards greater inclusion and understanding experience from the perspective of the person. This is largely as a result of an active human rights agenda within intellectual disability services and is under the commendable umbrella of promoting choice and reducing isolation. As such, it is still a developing area of research for those with more complex disabilities and with Down syndrome and dementia, for whom communication methods may not be verbal.

Had I kept my original intention, and sought a higher number of participants over a shorter period of time, I may have only communicated verbally as all three participants had greater verbal capacity in the first year of the research, albeit still very limited for Hannah and Lucy. This would have led me to understand different experiences of each of the participants. A key issue to emerge from my research was that diminishing capacity among people with Down syndrome was not an indicator of a person's ability to contribute. My findings concur with van Baalen et al. (2011) who maintained that marginalised groups have much to contribute in research, if given the opportunity.

7.7 Social model of disability

Being silenced has been a powerful form of oppression. Reclaiming the power for people to speak for themselves, rather than having others speak for them, has been a central demand of the social model. Yet, in my research this has to be set against people who are increasingly non-verbal and experiencing cognitive changes.

Although there is not one voice that can represent the many different experiences and views of people with Down syndrome and dementia, I have challenged the notion, and expectation, that ‘voice’ needs to be verbal in order to understand experience.

The social model of disability (Oliver, 1996) identified barriers, attitudes and social exclusion as contributory factors to marginalisation. My literature review, in Chapter Two, gave an overview of the changes in interpretation of the social model since its inception as a response to attitudes towards people with a physical disability. This showed how the model has developed over time, with some success, to include those with an intellectual disability, notably leading to changes in the lived environment and the development of accessible information. The social model was also shown to have been applied to people with dementia, albeit in a less convincing manner. There is less of an acceptance of increased dependency in some areas, whilst recognising ability to share experience and retain skills in others. Oliver (1996) did not originally intend the social model of disability to be all encompassing as a theory of disability. Instead, it was a starting point for viewing disability through a social constructionist lens, highlighting the negative impact of the social environment. Oliver (1996) originally suggested a threefold approach as being central to the social model, the need for:

- legislation that prevents anti-discriminatory practice and supports inclusion;
- more information to be given to disabled people;
- an infrastructure that recognises the needs and wishes of disabled people.

We are currently lacking a policy framework that adequately includes people with Down syndrome and dementia, other than to acknowledge that they exist as a separate group. If people with Down syndrome are not given information about their diagnosis of dementia, then they are excluded from contributing to decisions and making informed choices. Oliver's original premise offers a start to addressing the marginalisation of people with Down syndrome and dementia. This is by simultaneously trying to tackle discrimination and marginalisation at a policy level, and at an individual level by giving more information to people with Down syndrome and learning more about their experiences.

In future research, the social model of disability needs to be applied in a more focused way to this group, rather than just recommending it as part of a person-centred way of working. This involves the concept of active citizenship (Morris, 2005) and recognising individual ability to contribute, in direct contrast to social exclusion. It means recognising the role that people with Down syndrome have as experts in their own condition, concurrent with changing cognitive ability that requires increasing health and social care support. Instead, the reality that I observed was that Hannah moved from being marginalised and excluded in society, due to others' perception of her intellectual disability, to being marginalised and excluded within the care home. However, she was not alone as Lucy and Andrew also experienced exclusion and isolation, a loss of previously enjoyed relationships, withdrawal from social activities and having decisions made for them.

The ageing in place model introduced in Chapter Two demands that additional support is available, and requires staff training and knowledge if a person is to be supported to remain in the same accommodation. Similarly, if referral out is used, and a change in accommodation is made, the model by Janicki and Ansello (1999) requires this to be in the best interest of the individual with support put in place. Despite this, neither ageing in place or referral out proved beneficial in the longer-term for Andrew, Lucy or Hannah. We are currently lacking a framework that enables staff to develop as specialists in this area, incorporating both the ‘top down’ and ‘bottom up’ approaches. This would develop the in place progression model of small, specialist group homes, introduced in Chapter Two, which is currently seen more widely in Holland, Canada and the United States (Janicki et al, 2002,). In place progression offers dementia specific design, higher staff ratios, clinical support and training including end of life care. It remains important that this does not construct people with Down syndrome as passive recipients of care. On the contrary, there should be a move away from ‘care for’ towards ‘inclusion, contribution and understanding of’ as part of a citizenship approach that rejects the notion of institutionalisation.

I have to consider if, by suggesting a specialist model of in place progression, I am contributing to the problem. I have identified people with Down syndrome and dementia as exceptional and different; something that typically leads to stereotyping in a marginalised group (Cameron and Gibson, 2005). Whilst I accept that it seems contradictory, I am also aware that the very distinctive health needs associated with dementia in people with Down syndrome are at present unmet by non-specialist

services. As dementia is a progressive condition that will require increased medical intervention and end of life care planning, this means that social care and medical intervention cannot be kept separate. At the same time, this is not currently being discussed in a meaningful way if the person with Down syndrome is not aware that they are ill. The social model offers a framework, but needs re-evaluating in order for broader social processes to be included that are developed from the experiences of people with Down syndrome and dementia.

7.8 Summary

This chapter has demonstrated how lessons can be learned, both conceptually and practically, from the issues emerging from my research. I have highlighted the following areas of commonality as impacting on the experience of people with Down syndrome and dementia.

- Not knowing the diagnosis of dementia. This increases the potential for depersonalisation with an associated negative impact on well-being.
- The extent to which I was able to observe a sense of Self among participants, despite a lack of verbal communication at times. This reinforced the importance of social interaction, relationships and the need for meaningful activities.
- The importance of non-verbal communication as dementia progresses.
- The wider cultural difficulties that are extended when staff remain focused on either approaches to supporting people with an intellectual disability, or with

dementia, rather than a combination of both. This increases the potential for increased institutionalisation in generic care settings, with potential for this to be transferred to intellectual disability specific services unless an appropriate model of care is recognised.

The overlap between the gaps identified in the literature review in Chapter Two and areas of commonality between participants that increase social marginalisation has been reinforced in this chapter. Gaps in literature were identified as the lack of individual accounts of experience, lack of awareness of the number of people with Down syndrome who have dementia and the absence of literature and guidance that blended together approaches from both intellectual disability and dementia fields. This will be developed further in Chapter Eight where I also discuss findings in relation to my overall aim, highlighting strengths and limitations of the research and of my methodological approach.

CHAPTER EIGHT

CONCLUSIONS

8.1 Introduction

People with Down syndrome now actively participate in society, as do people with dementia. Paradoxically, in terms of representation and inclusion in research, individuals with both Down syndrome and dementia are far less visible. A contribution of this thesis has been in identifying that people with Down syndrome and dementia are able to convey their experiences and emotions if communication is adapted, and if an appropriate social environment is created to enable them to do so. This chapter demonstrates how far I have been able to advance this understanding as part of including people with reduced verbal communication in research, and why the approach that I took offers a methodological contribution to future studies.

Firstly, I discuss how taking this approach enabled me to identify the overall experience of participants as being excluded and further marginalised, with a reduction in social interaction and communication. I then review the limitations and strengths of my research process and continue to make recommendations for future research throughout, in order that the limited body of knowledge in this area continues to grow. In doing so, I consider how my flexible and synthesised approach, both to the methodology and methods of data collection, was a factor in

enabling the inclusion of participants as dementia progressed. My findings have highlighted the following areas as warranting further research:

- an understanding the process of sharing the diagnosis, or information about the diagnosis, with the person with Down syndrome and the impact that this has on both the individual, their family, partner and peers;
- a phenomenological investigation of the lived experience of dementia among participants with Down syndrome who are aware of their diagnosis;
- an ethnographic, comparative study between people with Down syndrome and dementia who are ageing in different accommodation settings;
- a qualitative study of the role of staff when supporting people with Down syndrome and dementia in different care locations;
- case studies with people who have Down syndrome and dementia at the end of life and their carers, to understand and address needs.

This chapter will expand on how the synthesised approach that I adopted can offer guidance to enable the future inclusion of people with Down syndrome and dementia in such areas of research.

8.2 Understanding experience

My research question in Stage One: ‘What awareness do carers have of the early signs of dementia in people with Down syndrome and what action was taken post-diagnosis?’ was explored in Chapter Three. I showed how early signs of dementia

noted by carers were consistent with those highlighted elsewhere in research, suggesting that a change in daily living skills was most apparent. The diagnosis was not routinely shared with people with Down syndrome leading to their lack of inclusion in future planning, and I evidenced a lack of awareness among carers of sources of information post-diagnosis. Stage One gave a snapshot of the lack of clarity among family and formal carers of how to plan ahead with, and for, the person they cared for with Down syndrome after their diagnosis of dementia. It led me to initially focus on an area identified as lacking both in Stage One findings and in research literature: what we know of the experiences of people with Down syndrome and dementia.

My research question in Stage Two was to identify factors that impacted on the experience of participants; revised after the realisation that lack of knowledge of the diagnosis meant that participants would not be able to comment on their own experience of dementia. The factors that impacted on experience were identified in Chapter Seven as:

- not knowing the reason for changes that were experienced, or no information about the diagnosis being shared;
- changing communication needs not being acknowledged;
- being defining by others based on their situation or additional need, rather than on an individual basis;
- not having their sense of Self, or identity, recognised and responded to;
- a lack of awareness of need, and opportunity, for social interaction.

The above factors were significant in the experience of people with Down syndrome and dementia being one of further marginalisation and exclusion, with reduced communication and social contact, consistent with Sheppard's (2006) criteria for marginalisation identified in Chapter Two. I will develop this further as I consider the strength of my research in advancing the limited amount of literature on people with Down syndrome and dementia, whilst also acknowledging the limitations.

8.3 Strengths of research

I have shown how opportunity can be created for inclusion and engagement with this population, through the longitudinal nature of the research and my methodological process. This is particularly important given the current need to monitor the development of a rapidly growing population of people ageing with an intellectual disability (McCarron et al., 2005). This section will reflect on how incorporating a phenomenological methodology was a strength of my research when exploring factors impacting on individual experience. It gave me time to develop a relationship with the three participants, and them with me. As part of a longitudinal study, I placed no restriction on the length of time I would spend with each participant or the number of visits, other than a maximum period of three years being identified initially for practical reasons. I was able to build up a relationship informally and flexibly with each participant. Ultimately, having fewer participants in a longitudinal study, albeit not my original intention, was crucial in developing relationships with participants.

A further strength was my use of a social constructionist approach which, alongside the development of relationships with the participants, allowed me to observe how participants were positioned through the use of language and communication. This gave insight into why those in society with the least verbal communication become the most marginalised. If an appropriate communicative response was not given, as expected by others, then social isolation was shown to increase. The spoken word is not only a tool for engagement, it is a contribution to how we construct our sense of Self. Without this construction Hannah and Lucy, with no verbal communication, legitimised the minimal attempts by staff to communicate appropriately with them. Meaning was not seen in their actions which resulted in the condition, either Down syndrome or dementia, being seen before the individual. As a result, behaviour was more likely to be viewed as deviant (Durkheim, 1960) or as posing a challenge to staff. Whilst I was able to observe Self and gain an understanding of experience based on the participants' verbal and non-verbal communication, this was due to the relationship that I built up with each individual and the time taken to develop non-verbal communication.

Consistent with Tuffrey-Wijne et al.'s (2008) research, people with an intellectual disability can contribute on subjects that are difficult or frightening, such as cancer or death. Adapting communication meant that I was able to successfully capture actions any interactions that may otherwise have been missed. Whereas I have acknowledged that use of video camera may have caught visual expressions, I am confident that I recorded this in my field notes and in the audio recordings of speech or noises made by the person, which expressed emotion in their tone. It does mean,

however, that there is no alternative version of data that can be referred to for verification or comparison of accounts.

My existing knowledge of literature on Down syndrome and dementia proved to be a strength as will be discussed when considering the relevance of a synthesised approach for future research, although required adaptation of a typical Husserlian phenomenological perspective. I did not bracket my existing knowledge as is recommended, instead I used it which I believe was the right thing to do in such an under-researched area. For example, I have demonstrated the scope for person-centred approaches in intellectual disability (O'Brien and O'Brien 2004; Walmsley and Johnson, 2003) to be incorporated with dementia-specific interventions (Kitwood, 1997; Sabat, 2002), something that is currently lacking in research literature, policy and practice. My findings suggest that this is not only relevant, it is essential. I took this further by incorporating Nolan's relationship-centred work (Nolan et al. 2006) with Sabat (2002) and Kitwood (1997). This integration of research and theory from intellectual disability, dementia and chronic illness was a contributory factor in enabling my understanding of individual experience, and highlighting the current crossroads in care for people with Down syndrome and dementia.

8.4 Limitations of the research

Limitations of Stage One of the research were considered in Chapter Three: lack of direct contact with those completing the questionnaire and the lack of an exploration

of communication methods. Ensuring the inclusion of people with Down syndrome and dementia remained an aim throughout the research process and I revised my approach due to the lack of diagnostic disclosure to the three participants. On reflection, whilst my original aim may have resulted in research that informed specifically about the experience of dementia, I had not included time to find out what each participant actually knew about the condition. This may have been very little had an explanation not been given along with the diagnosis. In any similar or future research, ascertaining the knowledge base of participants about their condition would be a requirement at the outset, even if they have a diagnosis.

A small sample size in Stage Two means that I cannot claim to describe, or understand, factors influencing the experiences of people with Down syndrome and dementia generally. Instead, I am able to offer a perspective that may be common among some who are already marginalised due to their intellectual disability. The impact of the lack of a shared diagnosis was ever-present. I would have felt more comfortable had each person been given some information about their health. As a researcher, I was complicit in what felt like deception, something that I was not comfortable with. Equally, family and formal carers were complicit; no one suggested to me during either stage that any of the participants should have been told of their diagnosis or queried why this had not happened. I reflected during the research whether, in terms of validity, I should have extended the involvement of staff in Stage Two in order to seek their views in relation to each participant. I had only gained consent from carers for Stage One of the research, rather than Stage Two. Had I done so, this may have given me an understanding of why the diagnosis,

or related information, had not been shared. However, although this is an area of research that I recommend is conducted in the future, I remain convinced that to do so would have undermined the role I was trying to give to participants with Down syndrome. This was an ongoing dilemma that ultimately I did not resolve satisfactorily.

With hindsight, this could have been avoided by extending the consent period to cover more participants during the whole research, so that carers in Stage One were also included in Stage Two. The British Sociological Association (2004) state that participants must be informed of all ways in which the data may be used in the future. I am satisfied that in both stages the staff were aware of my role; I mentioned this verbally on my arrival as I reintroduced myself, just as I reaffirmed consent from participants on each visit. I also gave an information sheet to staff at the start of Stage Two. This advised of why the research was taking place, that consent had been given by the persons they cared for and that I would be recording conversations and observations during my visit. At the time, I thought that I was doing this as courtesy to the carers. However, I have come to increasingly see the ethical significance of this. I did not electronically record staff voices or conversations or any interaction in public areas. Should staff have entered the room, or spoken when the voice recorder was on, I immediately alerted them to this and deleted the interaction, despite usually being told that this was not necessary. Although I felt that it was essential to constantly renew consent with participants as a result of them having dementia, I did not revisit this formally with staff. Indeed, had I done so I believe that this may have

been become viewed as time-consuming at best and at worst annoying as I, and my remit, became very familiar with staff due to the longitudinal nature of the research.

I have debated whether my methodological approach was a strength or limitation of the research, ultimately considering it to be both. I chose to focus on how participants communicated and engaged with me about phenomena generally. The lack of awareness of their diagnosis of dementia was a crucial factor in this process, and relevant in my decision not to use IPA, as discussed in Chapter Four, with its emphasis not only on verbal communication, but also on interpreting experience and understanding of specific health research. Referred to as the ‘double hermeneutic’ by Smith and Osborn (2008) this would have meant that I was trying to make sense of the participant, who was also trying to make sense of their experience - but without having information about what that experience actually was based on. This raised an ethical dilemma for me and with reflection, although I opted for a more general stance particularly around methods of data collection and communication, it offered me a more flexible approach. It did not leave me requiring an ‘imaginative leap’ (Smith and Osborn, 2008) from my data to my findings.

8.5 The relevance of synthesised research methods in future research

Taking a mixed method approach meant that I was able to develop Stage Two from the evidence in Stage One; this was important due to the lack of previously published

research on which to base my research question. It also offered more complete evidence than qualitative or quantitative research alone and did not restrict me to one method of data collection; an approach that I will consider in relation to its relevance for future studies. Although not intending to compare the results, the qualitative and quantitative stages of my research were complementary and offered a continuum. This ranged from carer experiences in Stage One highlighting a lack of the inclusion, to people with Down syndrome and dementia in Stage Two and my identification of factors that contributed to further exclusion. Whilst Stage One was not essential for planning Stage Two, the inclusion of a postal questionnaire and case studies enabled me to accommodate the strengths of both approaches. Each was appropriate for the group in question in both stages as discussed in Chapter Four. Similarly, by synthesising my research methodology in Stage Two I was able to maintain the inclusion of participants for the duration of the research. In doing so, I have demonstrated how non-verbal communication and changing capacity can be incorporated into qualitative methods to complement the overall research design. In this section, I will explain why I recommend such flexibility for future studies, particularly in an under-researched area, and in doing so I highlight areas that may continue to prove challenging.

An opportunity created by combining a phenomenological approach with its descriptive elements, and narrative and ethnographic methods that incorporated reflexivity, observation and choice in communication, was that I identified unintended consequences. An example of this was my observation of increased isolation among all three participants. This was evidenced by Andrew with an

increased reliance on mice and a teddy bear for companionship. I observed this in Lucy's experience as she had become physically removed from her friends with ongoing contact not supported and with Hannah, isolated within a care home for older people. This led to my awareness of the importance of a relationship-centred approach that emphasises the relationship with friends in addition to the recognised triad of family, professionals and the person with Down syndrome. Unintended consequences are a feature of phenomenology, yet may have been missed had I not conducted the research over three years, if I had not remained flexible to the changing communication of participants, and if I had not combined this with Yin's (2010) two layered approach to analysis: individual and cross case comparison, which added further depth. Longitudinal research offers the same opportunity in future studies to gain a greater understanding of individual experience by taking time to develop relationships and adapt communication.

Although advocating a flexible approach, I had a clear structure as explained in Chapters Four and Five. Traditional research methods of interviews or questionnaires, although appropriate for a geographically dispersed group of carers in Stage One, did not lend themselves to the inclusion of participants with changing cognition and communication, and future research should also incorporate this awareness. Whilst a questionnaire may give a snapshot 'at that point in time' from the perspective of the person with dementia, it is unlikely to convey or understand experiences.

Developing an approach that enabled me to be led by the participants gave a greater opportunity to focus on what was important to each individual. By increasingly incorporating non-verbal methods of communication, I was able to maintain engagement and interaction with each individual as dementia progressed. Non-verbal and visual methods added depth to a complex research paradigm meaning that pictures, observation and non-verbal communication offered a rich insight. Having this flexible approach to my methodology and methods proved to be invaluable when conducting research with a typically excluded group. I have shown how their inclusion has been possible by:

- taking time to individualise the method of communication with each participant;
- using non-verbal conversation as a means of engaging with participants, rather than a typically verbal approach;
- not looking for chronological information;
- recognising the importance of the physical environment in providing additional, objective data;
- recognising the importance of silence.

I combined this with a phenomenological stance, supporting reflexivity, by allowing time to develop a relationship with each participant, letting the participant choose the length and location of each session, maintaining flexibility in approach to communication as dementia progressed and synthesising elements from ethnography and narrative research. The use of case studies added academic rigor as I

incorporated cross case analysis along with individual analysis. Case studies brought the research to life by telling the story of each individual; voices would otherwise remain unheard. Combined with the longitudinal nature of the research, this meant that I was able to observe subtle changes over a longer period of time. For example, this is how I came to understand Hannah's emotion through the tone and expression in the noises she made, giving an indication of her preferences and feelings. This is something that may be missed in research that is reliant on verbal communication, or that takes place within a shorter timeframe. Use of case studies is an approach that I recommend in future research, if appropriate for the individual and the phenomena being studied. In the relatively small population of people with Down syndrome and dementia, even a small number of case studies that identify the same features will signify the emergence of a pattern, and will further develop the knowledge base in this area with much needed research.

I initially relied on my understanding of both intellectual disability and dementia, and came to realise the importance of this as I gained confidence in changing my approach on an individual basis with each participant. This included recognising that Hannah wanted to eat when she was unable to do so, and interpreting her body language when she was in pain. It meant that I looked for other options when Lucy did not recognise the first style of pictures that I showed her. My conversational style, consistent with a phenomenological emphasis on description, is a further approach that I recommend in future studies as a means of understanding experience. I maintained interaction and communication with Lucy through to the end of her life and was able to focus only on each participant with Down syndrome, rather than

filling gaps with information from carers or family members. However, the role of carers is one that should be recognised and is an area that also warrants future investigation, with staff, parents and siblings. I have not been able to comment in detail based on my observation of the activity, or inactivity, of staff in different settings. However, I have made suggestions about the need to transfer learning between intellectual disability services and dementia services to avoid the current missed opportunity for both services to learn from each other. Further research, which should include both interviews and observation, would be beneficial in gaining greater understanding of why staff interacted with participants, or conducted themselves as they did. Whilst I have advocated incorporating a relationship-centred approach in practice, it is only through future investigation that its value can be demonstrated. For this reason, I recommend a social constructionist view of Down syndrome and dementia that is based upon learning from both fields. This is to build upon a personhood approach (Kitwood, 1997), increase the importance of a relationship-centred approach (Nolan et al., 2006) and develop awareness of the need to understand individual senses of Self (Sabat, 2002).

My synthesised approach contributes to future research with people who have limited communication by moving towards ‘how’ we include people rather than ‘if’. Other groups with communication difficulties, and those with complex disabilities, are also frequently excluded from research, as highlighted in Chapter Two. I have shown that inclusion is possible by using creative and flexible methods of communication that reduce the reliance on verbal communication. My findings are consistent with French and Swain (2001) who wrote that barriers to effective two-way communication are

found in institutional practice. By placing a greater emphasis on listening and observing, rather than speaking, we can enable research in a more collaborative sense. Recognising the importance of van Manen's (1982, pg. 294) 'art of being sensitive' through listening to the silence, and incorporating this into the research findings is particularly important when trying to build up knowledge in an under-researched area. Equally important within my research, and essential in future studies, was that I had high expectations of the participants, and that from the outset I welcomed the possibility that our engagement may become non-verbal.

8.5.1 Challenges for future research

The challenges of adopting such a flexible approach should also be recognised in future research, for example I have noted that my informal approach, although crucial in developing a relationship with participants, may have contributed to the impression that our meetings were for social rather than research purposes. Whilst the relationship that I had with each participant was a contributing factor to successful inclusion of participants, it must also be identified as a risk for future research if time is not available for such a relationship to develop.

Researchers need to evidence a willingness to widen their understanding of communication to incorporate non-verbal exchanges. My adaptation of 'narrative' as 'communicative' enabled me to increasingly emphasise the importance of non-verbal methods. However, this may not be the most appropriate approach if a specific research question requires a verbal response. My contribution here has been able to

offer a flexible approach that is based on the changing needs of the participant, rather than a fixed need of the researcher. Future research should continue to acknowledge that capacity is not always conveyed verbally. For example, I became aware that Lucy understood me when she touched her hair after I commented on how nice it looked, and similarly when Hannah opened her mouth after I asked about her teeth. Although a practice rather than consent situation, both examples indicate a level of understanding that would not be apparent from verbal communication only. The issue of informed consent caused me concern and leads to my recommendation of greater clarity over the ethical process before any future research begins, to acknowledge and incorporate the changing capacity and communication of participants. Equally concerning was my observation of locked units in the care home along with a restriction of freedom for Hannah, something that needs to be addressed in a human rights context.

For people with Down syndrome, taking part in research about the lived experience of dementia can only happen if the diagnosis of dementia is known by participants. This lack of awareness impacted on my chosen approach and will continue to do so in future research unless there is a clearer understanding or guidance on sharing information about dementia. Clare (2005) identified two forms of narratives among people recently diagnosed with dementia. The 'self-maintaining' narrative is evident when dementia is viewed as a normal part of ageing. However, this cannot apply to people if it is not openly acknowledged or discussed. The 'self-adjusting' narrative acknowledges that dementia will bring about changes that can be integrated into a person's life. This will also require knowledge of the diagnosis in future research. A

further challenge is how to include people with Down syndrome and dementia in participatory research, in the same way that people with an intellectual disability and people with dementia are included. This would involve collaborative research in planning and conducting the study. It would also involve participants having a degree of control over the process (Walmsley and Johnson, 1988). Again, this cannot happen as it does in the general population, even with someone with Down syndrome in the early stages of dementia, if potential participants are not aware of their diagnosis.

Reflecting on my research aim and question, I have been able to address some of the gaps identified in the literature review by:

- presenting individual accounts of experiences;
- developing two-way interaction on an individual basis as dementia progressed;
- developing a relationship with the participants with acknowledgement of, and response to, sense of Self;
- incorporating literature and theory from the fields of dementia and intellectual disability.

However, in taking this approach there are questions that remain unanswered; we still do not know enough about the lived experience of dementia in people with Down syndrome to confidently develop an infrastructure that addresses needs and wishes. Nor can I claim to have relayed information about previous experience or

specific opinions, to have provided evidence of statistics or to have investigated the role of staff in supporting people with Down syndrome and dementia. These are all areas that remain gaps in literature. Future studies will be able to develop my research findings and also incorporate a synthesised, flexible approach to methodology and methods of data collection to support inclusion.

8.6 Concluding remarks

This thesis constitutes a study of factors that impact on the individual and collective experience of people with Down syndrome and dementia. In a wider context, it has highlighted the process of marginalisation and exclusion at social and cultural levels. It is disappointing that, in the seven year period since beginning this research, the amount of research with people who have Down syndrome and dementia has not substantially increased. This is a period which has seen the development and launch of dementia strategies in England, Wales, Northern Ireland and Scotland. Whilst the framework is in existence for areas of development and research, it remains incumbent upon individual researchers to improve the inclusion of people with Down syndrome and dementia, by adapting communication and challenging the relevance of traditional research strategies. Whilst I incorporated a synthesised approach and flexibility in my methodology and methods, this was within a clear framework. Having this methodological clarity offers an approach that I recommend in future research with people with Down syndrome and dementia, or others with changing cognition or capacity. However, I would add the caveat that this is alongside adapted or non-verbal communication and that the role of the researcher is crucial including

having prior understanding of the condition in question, in this case Down syndrome and dementia, as a starting point to developing a relationship with the participants.

I have come to realise through the research process that inclusion at policy level should not just identify that a link exists between Down syndrome and the early dementia. A more proactive approach is needed with specific guidance over the long-term support for individuals with Down syndrome and dementia. The knowledge and expertise of people who use services should be valued using communication methods that each individual is familiar with. This means consulting appropriately with people who have Down syndrome and dementia, and who are aware of their diagnosis, recognising their role as experts in their own condition. What I have achieved is to highlight that a fundamental shift is needed in how people with Down syndrome and dementia are perceived. From the outset, I wanted to challenge the assumption that not having speech should not preclude an individual with Down syndrome and dementia from participating in research. This supports Williams' (2012) statement that research should not only focus on those with a literal voice. However, I also agree with Thurman et al. (2005) that the responsibility lies with the researcher, to instigate and maintain a relationship. By ignoring the contribution made by those who are considered untypical in research, the process of exclusion and marginalisation will be continued.

Since beginning this research, discussion has begun between the Scottish Consortium for Learning Disability and the Scottish Government to collate statistics on the number of people with Down syndrome in Scotland. This is to assist with future

planning for conditions relating to ageing, particularly dementia, and will address a key factor in the marginalisation of this population, that of a lack of available statistics as identified in Chapter Two. Hopefully, this will be a step towards more cohesive future planning to enhance the well-being of people with Down syndrome and dementia and reduce the inevitability of their marginalised status. The experience of Lucy, Hannah and Andrew suggests that this is imperative.

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